Chapter 6

Caregivers of People Living with Mental Disorder: Bridging Epistemologies

‘I have moved heaven and earth to help Yezizaad.’
– Meher Bharucha (on helping his son, diagnosed with schizophrenia eighteen years ago)

The previous chapters looked at three different sets of practitioners and their practice/work, vis-à-vis people living with mental disorder. The first was psychiatrists as an instance of a modern, professional, rational and biomedical system based on a scientific epistemology. Next was Ayurveda and its practitioners as an instance of an indigenous, professional, codified system of medicine based on a mixed epistemology that incorporated the rational with the metaphysical to a certain extent. The last was traditional healers and their healing practice as an instance of an unorganised, non-institutionalised, community based, socio-cultural practice wherein the practitioner addresses problems predominantly through a cosmological/metaphysical lens. Traditional healers were also the least organic/biological in their orientation. All three sets of practices are based on disparate ontological and epistemological principles, and depending upon the fluidity of the latter, their interface with other practitioners is determined. They thus may or may not interface with each other depending on how they view their own practice.

Apart from the nuances of a given system of practice and of the individual practitioners within it, another crucial factor determines the interface between the otherwise apparently incommensurate practices. These are the people who consult these practitioners for their myriad problems including mental disorder. In other words, the people living with mental disorder and their caregivers play an extremely crucial role in bridging epistemologies of different systems of practice. All the practitioners from the three systems who were interviewed spoke about their clients seeking help from ‘other practitioners’; they also mentioned that they were not necessarily the first on the caregiver’s preference list. Caregivers, thus, emerge as a central category with respect to interface between practitioners. Unlike the beliefs and ideologies that is held by the practitioners, that at one level cohere them together into an integrated whole, families and individuals hold what Arthur Kleinman (1980: 95) describes as a more ‘idiosyncratic’,
wide-ranging sets of beliefs. Peter L. Berger et al. describes them as ‘individual packages of ideas, no two of which are exactly alike, made by assembling components from various systems of belief’ (cited in Kleinman 1980: 95) These ‘cognitive packages’ (ibid.) in turn contribute to the repertoire of meaning systems and add to plurality in health care.

Kleinman also posits a model where health care is described as a ‘local cultural system composed of three overlapping parts: the popular, professional, and folk sectors’ (1980: 50). The popular sphere within this model is deemed to be the largest and also the least studied. Kleinman describes it as a ‘matrix’, comprised of several levels including the ‘individual, family, social network and community beliefs and activities’. He further lays down that it is in the ‘lay, non-professional, non-specialist, popular culture arena’ (ibid.) that illness is first defined and any kind of health care activity is initiated. When people seek the help of a folk or professional practitioners, he says that their ‘choices are anchored in the cognitive and value orientations of the popular culture’ (ibid.). In fact, even after receiving treatment, they return to the popular sector to evaluate and figure out future plans. The popular sector, according to Kleinman is the ‘nexus of the boundaries between the different sectors; it contains the points of entrance into, exit from, and interaction between the different sectors’ (ibid.: 51). The commonplace understanding is that the professional sector decides and organises health care including treatment modalities for people; but, according to Kleinman, it is the lay people who ‘activate their health care by deciding when and whom to consult, whether or not to comply, when to switch between treatment alternatives, whether care is effective, and whether they are satisfied with its quality’ (ibid.). Caregivers are a part of the popular sector and, accordingly, a whole range of options opens out.

The caregivers, including the family, as well as the patients are central to accessing and entering the entire health care sector, including the professional and folk/traditional sectors. They are central to perceiving, experiencing and reporting symptoms; to labelling a disease, sanctioning a range of sick roles, including acute, chronic, impaired, medical, psychiatric and so on; figuring out what to do and whom to consult, the first time and subsequently; and applying the treatment prescribed and evaluating the results of therapy received (ibid.). The family’s cognitive structure and beliefs and values will have a profound impact on the above process. An active interaction and engagement with multiple sectors or practitioners is thus possible. Once they enter a particular sector or come in contact with a particular category, they in effect encounter a different set of beliefs and values because the ‘clinical realities of the different sectors and their
components differ considerably’ (ibid.: 52). This reality will definitively shape the illness and therapeutic experience. While the professional sector like that of psychiatry might be deemed to have a more profound effect, because it is organised and institutionalised with the backing of a definitive and powerful history as well as a global presence and uniformity of procedure and access to advanced technology, in comparison to traditional or folk healers who have a more diffused presence with hardly any resources. The caregivers and patients access them both, simultaneously, successively or concurrently and do so irrespective of the apparent advantages that modern medicine is deemed to possess. In other words, the decision that this set of people make with regard to health care choices and accessing the health sectors is dependent on a different set of assumptions and principles. How this decision is made is a very important question. Scholars have shown that the health care system is ‘much wider than the boundaries of the modern medical profession’ (Kleinman 1980: 58).

The three sets of practitioners as exemplars of different sectors comprise a complex matrix that caregivers and patients constantly negotiate and engage with. And, in doing so, they open out and create avenues for interface. They thus comprise an immensely significant stakeholder and need to be engaged with to draw some insights about how and why health care choices are made.

To begin with, beliefs about illness are closely tied to beliefs about treatment. Some of these may seem bizarre and untenable to modern medicine, but lay people are not really concerned about such things as ‘theoretical rigour’ as much as they are about the ‘treatment options’ (ibid.: 93). This kind of engagement can also result in conflict and can be a difficult experience.

The caregivers and their role can be analysed by examining both within the frame of an important semantic distinction between disease and illness. This distinction is underlined by separate ontology and epistemology that comes into play and determines health care choices made by lay people. While disease is the specialisation of the professionals, illness as a category is what caregivers engage with primarily. Disease has been defined variously, but it primarily refers to a pathological condition or a malfunction or impairment of psychological or biological processes that affects an organ, part or system of an organism and can result from a host of factors from a localised infection to genetics and the environment as well. It is also deemed to be characterised by an identifiable set of signs and symptoms. Illness, according to Kleinman has been defined as
... secondary personal and social responses to a primary malfunctioning (disease) in the individual’s physiological or psychological status (or both)...also included in the idea of illness are communication and interpersonal interaction, particularly within the context of the family and social network...illness is the shaping of disease into behavior and experience. It is created by personal, social, and cultural reactions to disease (1980: 72).

Disease and illness then can be seen as different interpretations of a clinical reality. Different systems of health care would differ in how they address disease and illness. A modern system like psychiatry or biomedical model is more disease oriented, but practitioners may or may not strictly follow the biomedical norm. Indigenous systems, like Ayurveda, though are also disease oriented also take into account illness concerns, to a greater degree than biomedical systems (ibid.). And folk and traditional systems often take into account primarily the illness experience of a patient or caregivers and accordingly provide treatment. Health-seeking behaviour is determined by a complex interplay of factors including this dichotomous distinction between disease and illness. Health-seeking behaviour and health care responses are also the result of a complex interweaving of biology and culture. This interplay is also what allows for interface between ostensibly divergent practices.

This chapter will primarily look at caregivers and how they respond to the challenging and confounding experience of having to seek help in order to address the issue of a family member suffering from mental disorder. Within the context of my research it was very crucial to examine their position especially with regard to the practitioners. The interviews conducted with the latter revealed that their clients/patients accessed different practitioners. It was important to now speak with some of the caregivers to understand how they responded to mental disorder, and whether this response repertoire included approaching more than one practitioner and system and, if so, why. The main attempt of the interview was to ask whether they accessed more than one practitioner and what primarily determined the choice of the system and also the practitioner.

In all, I interviewed forty caregivers of people living with mental disorder. These caregivers may or may not have had contact with some of the practitioners I had already interviewed; at least, not all of them. I used purposive sampling to identify the caregivers whom I interviewed.

I spent a week at a Psychiatric OPD (Out Patient Department) of a semi-private teaching hospital in West Mumbai. The Head of Department was a senior psychiatrist
whom I had earlier interviewed as a part of my study. I also approached a non-profit organisation that has a day-care centre for people living with mental disorder. I was able to interview caregivers who have been associated with or were associated with the day-care centre during the time of the interview. The hospital interviews were conducted on a one-to-one basis outside the Department, at the waiting area while caregivers and their wards waited for their turn to consult a psychiatrist. Some had come to collect medicines and to meet the doctors with fresh reports as a part of their follow up visit. A few were admitted to the hospital ward as well. The caregivers associated with the day-care centre were first contacted over telephone. I met two families in person who gave me permission to visit them at home. The rest of the interviews were conducted over the phone. One caregiver refused to give me an interview altogether.

The purpose of the interview was to understand a caregiver’s perspective of mental disorder and how they responded to it. The main crux was, however, to understand if they had approached or were seeking help from multiple practitioners and, if so, why. This was in line with the larger purpose of the study which was to examine the possibility of epistemological bridges across various systems and practices that are otherwise incompatible. Do caregivers access these practitioners concurrently or contiguously? Does it have any connection to their perceptions about mental disorder? Before examining the details of the responses, some findings can be put forth in general terms that applies to all caregivers that were interviewed.

Excepting two, all the caregivers I interviewed had accessed more than one practitioner and also accessed more than one system. The order and preference, however, differed. Only two caregivers explicitly told me that modern biomedicine as a system and psychiatry, in particular, is all that they had approached from the commencement of the problem to the time the interview was conducted. Homeopathy had been accessed a few times; no body mentioned Ayurveda specifically, but all had accessed various kinds of traditional healers before and after contact with a psychiatrist.

A caregiver’s religious identity is an important factor that needs to be mentioned. Caregivers generally approached a healer from their own community, be it the language group or even religion, to begin with. But, if the mental disorder did not ameliorate, the tendency was to approach any healer irrespective of religious background or leanings. But there were exceptions. With some of the caregivers this was not so; they approached a healer from a religious orientation different from theirs, because of the reputation of a particular healer. Caregivers, by and large, went to healers associated with all religious
communities and spaces; excepting the Muslim caregivers who did not mention going to a temple. But a Hindu patient would be taken to a Muslim healing shrine as much as seeking help from a temple priest.

The caregivers own perceptions about mental illness also determined this choice. It was difficult for caregivers to explain the reason for mental illness in modern medical and psychiatric parlance. References to the ‘head’, ‘mind’ and ‘brains’ were made. But most explained the problem at length and associated aetiology to cultural rather than organic causes. So, fear after having attended a funeral was often given as the cause of mental illness and also the inception of it. Guilt was another associated factor. Hence, a young Muslim girl who had an abortion started to ‘behave strangely’ after she came back from the hospital. The psychiatrist diagnosed her to be suffering from depression: she is afraid, unable to eat and sleep; she is often short-tempered and unable to look after her other children or participate in household chores. Her parents look after her. For them, mental illness has been a debilitating, anxiety-ridden, debt-ridden, and ostracising and a completely perplexing experience.

The kind of mental disorder, the magnitude of the problem along with the length of duration, the level of amelioration or deterioration of the affliction were also important considerations that determined seeking out and accessing more than one system of health and healing. The primary caregiver was an important figure in making this decision as well. In a few instances, the primary care giver initiated contact with a traditional healer first before taking the ill family member for consultation.

The caregivers did not always consult a practitioner first. Depending on how the problem was perceived, help was accordingly sought. The popular sector, to use Kleinman’s term (1980), was the first contact of the caregivers before seeking help from a practitioner. Behavioural problems almost always first saw a consultation with other family members and extended family and other social networks in the caregivers’ life. Aggression, withdrawal, excessive fear, excessive anxiety, insomnia were some of the problems spoken about by the caregivers. Various suggestions were followed through by the caregivers that sprang forth from this popular sector. Amongst a myriad of suggestions to deal with the errant person was also those suggesting that the care giver seek help from a healer and also a ‘doctor’, or psychiatrist. Often a relative or friend had also availed of the services of the same practitioner and accordingly provided a reference. Thus, there is a close network between the popular sector and the professional sector, an interface that
in turn determines what shape and significance is assigned to further contact with the professional and traditional/folk sectors.

Another important feature that was encountered in the course of the interviews was that of physical ailments of the patients/clients that added to the burden of caregiving. The caregivers mentioned their wards suffering from a range of physical ailments. They can broadly be divided into chronic and acute as well as pre- and post-diagnosis of mental disorder. Some identified as showing up prior to the onset of a diagnosed mental disorder and some post the diagnosis. Alcoholism was a common complaint reported. Tuberculosis, HIV (Human Immuno Deficiency Virus), diabetes, insomnia and hypertension were the other reported disease conditions. A whole set of physical ailments were also reported post the diagnosis of a mental disorder. These included weight gain, thyroid problems and hormone imbalance. Some of this was reported to be a side effect of the anti-psychotic medication that was taken by the wards.

It is to be mentioned that, along with their wards, the caregivers themselves also reported various physical ailments, again distinguished pre- and post-diagnosis of mental disorder of their ward. Some they identified as stress related and some connected to the sheer amount of physical work associated with the caregiving role. For instance, getting a sick person to the psychiatrist which could mean travelling anywhere between half-hour to over four hours depending on the location of the hospital and changing modes of public transport. Old-age-related problems were also encountered. Examples included joint pain, severe back pain, hypertension and so forth. The older caregivers found this to be particularly perplexing and a cause of immense concern. These older caregivers, mostly parents, also reported concern about who will take over the caregiving role after them, reflecting upon the lack of support systems present and accessible.

Another common feature that most caregivers spoke about and a cause of worry for them was the financial burden of having to look after a person with mental disorder. Modern medicine was seen by all as an expensive proposition. Medicines that were otherwise prescribed for a life time were often stopped because of the cost implications for the family. If the person affected is the sole earning member, this burden is felt even more acutely. Livelihood is also affected if the sick person is the wife and has the caregiving role otherwise. A nuclear family is particularly affected here because the earning member or the spouse has to forfeit work to assume the caregiver’s role, not just of the sick spouse, but as in some of the cases the children as well.
There are then a whole range of behaviour and roles that has to be assumed as caregivers. It is a multidimensional role and includes physical, psychological, social, financial and medical aspects all of which need to be carried out simultaneously.

Profile of Caregivers

The caregivers differed in their economic and socio-cultural profile. Questions pertained to their age and background, where they were from, place of residence, how did they earn a living and so on. Next who were they involved in looking after, or who was ill and how were they related to the ill person. Questions were also asked pertaining to the illness itself. For instance when did the person first fall ill and what was the problem that made them seek help. Finally, questions were asked about how they responded to the illness, especially in terms of seeking help; who did they seek help from and why. The formal diagnosis by the psychiatrist was not always known unless the caregivers mentioned it themselves, since I did not have access to their medical files. Most times I asked them what the problem was.

The home visits yielded the best interviews in terms of the range of information in accordance with the questions formulated. The ones conducted in the hospital did not provide similar results; time was a problem here. I was able to speak with the caregivers whilst they waited their turn to meet the psychiatrist with or without their wards. Sometimes I spoke to them while their wards were meeting with the psychiatrists. There was a general air of urgency at the hospital and the interviews were underlined by a general sense of anxiety, anticipation and also impatience stemming from a need to complete all procedures as fast as possible so they could leave. The presence of a ward, as was the case most of the time, saw the attention of the caregiver divided between me and keeping an eye on their ward. At such times, I skipped the first few questions pertaining to their background and after a brief introduction directed my interview to asking them about how they dealt with their caregiving role.

Assuming the caregiver’s role has its set of challenges. For some, it had become an almost indelible part of their schema, or cognitive framework. For parents, it was just an extension of what they already did, that is look after their children. In the context of mental disorder, however, assuming a caregiving role was a difficult experience. It brought into fore a separate set of requirements from everyday caregiving which most of the respondents were already involved in as parents, spouses and children. Caregiving for
them was not just managing a sick person, but also managing his or her hospital and
doctor’s schedules, treatment prescriptions and proscriptions and all related work. It was
physically and mentally daunting.

Caregiving is a significant issue in the treatment and rehabilitation of persons
suffering from mental disorder. Families, by and large, view caregiving as their
responsibility. Research shows that, in India, a majority of people with severe mental
disorder live with their families (Thara et al. 1998; Murthy 2006 cited in Janardhana et al.
2011: 406). This is just a reflection of the poor public health status vis-à-vis support
systems as well as preventive and curative response to mental illness/disorder. This
lacuna is what results in families ‘having to shoulder greater responsibilities of caring for
their mentally ill family member’ (ibid.). Janardhana et al. posit that it is ‘difficult to
conclude whether this is by choice, cultural influence or lack of facilities, though there is
some evidence to support the fact that family involvement in care was and continues to be
a preference of families’ (ibid.).

Background
The age of the caregivers ranged between eight as the youngest to above sixty as the
upper age limit. Not everyone was able to state their exact age. An approximate age was
given or guessed. All caregivers interviewed shared a kin/blood relation with their wards
or the ill person; they were all parents, siblings, aunts and uncles, cousins, children and
spouse. Mostly they were parents and spouses.

I interviewed caregivers from all communities – Hindus, Muslims, Christians and
Parsis. The caregivers were not identified in accordance to their religion, but rather
approached in order of accessibility. One caregiver had mixed parentage: a Muslim
mother and a Hindu father. Information about their religious orientation was sought in
order to determine if it was a consideration in choosing a practitioner especially a
traditional healer. All interviews of caregivers were conducted in Mumbai. All the
caregivers were residing in Mumbai during the time the interviews were conducted and
had sought help from various practitioners in the city, but they had family in villages
spread across Maharashtra and Uttar Pradesh, Andhra Pradesh and Gujarat. Some of the
caregivers moved between states sometimes with their wards and consulted practitioners
across. A few stated that their first contact with a traditional healer was in their village
and having failed to see an improvement they moved to the city.
The profession of the caregivers included auto and taxi drivers, newspaper vendors, small traders, a lawyer, students including one pursuing a Ph. D degree, a former bank employee and factory/company employee. Some of them were housewives and a few were unemployed as well. This information was sought in order to determine if it was a consideration in choosing a system or practitioner, especially in terms of the financial aspects and consideration as well as awareness and education. The caregivers thus ranged between what could be loosely described as lower middle class to middle class and also a couple of instances of upper middle class.

**Perception of Mental Disorder**

A large part of the interview focused upon the caregivers’ experience of dealing with a close family member suffering from a mental disorder. Questions were asked about the age of onset of the illness. This varied anywhere between six months from when the interview was conducted to the upper limit of twenty-eight years. Most were between five and ten years. It was difficult for caregivers to exactly pinpoint the illness in terms of time because perceptions about mental disorder differed. Sometimes the caregivers remembered when the problems started without necessarily remembering when a doctor/physician/psychiatrist first diagnosed the condition. At other times they remembered the psychiatrist defining the behaviour as a disease condition but not when the problem behaviour started. At other times, they were not able to precisely remember when it started, but only an event that brought the condition to the fore.

Very often how they remembered was closely related to how they saw the problem and defined it. So, a daughter would be described as always being quiet and an introvert, but not necessarily fearful, till a certain time when it became pronounced and its magnitude increased, enough for the family to seek medical help. In another instance, an eighteen-year-old college going girl from a middle-class Gujarati family started to act ‘strange’ after coming back from a late night party. She is thirty-six now and was diagnosed with schizophrenia years ago; her parents do not remember when. They have been through a long list of psychiatrists. In fact, they knew quite a few of the psychiatrists that I had interviewed for this research.

Often the experience was first shared or witnessed by close family members or a social network in the form of a community, at a locality level or at a village level. Then the first response was in accordance to suggestions provided by this network or what Kleinman (1980) terms the popular sector. This could include a range of responses from
talking, counselling to even scolding as well as referral to the professional or folk/traditional sector. Thus, when a mother became withdrawn, refused to eat or sleep, was constantly fearful, her son studying in Mumbai brought her to a psychiatrist while her extended family back in the village had sought the help of a healer. She thus moved from the village to the city keeping within the boundaries of her social network.

Almost all of the caregivers who were interviewed were not previously aware of diagnostic terms like schizophrenia or depression. The exceptions were the educated respondents, like the lawyer, the retired bank employee and the Ph D student. Most found it difficult to pin point the beginnings of mental disorder of their wards. Some, as stated earlier, were able to connect it to a specific event like a funeral, a miscarriage, a hospital stay or a late night out. They then believed that the onset of mental disorder was closely associated with the event. Some also spoke about mental illness as the effect of black magic, the result of someone having ‘done something’. Alcoholism was also seen as a cause of mental illness. While almost all identified dimaag (mind/brain) as the area that gets affected in mental illness, they expressed ignorance as to why mental illness happens. Some did say that more than one person in the family suffers from it, hence it transfers through lineage. Others said that a traumatic experience was what brought mental disorder about. Most explanations tended to veer towards socio-cultural understanding of mental disorder and rarely an organic cause was put forth. I am presenting some of the findings below by examining the responses of a few of the caregivers, to provide an idea of the issues that assuming the caregiving role has brought about. For a complete list of all the caregivers interviewed and the issues examined, refer to Table 6.1.

Sabina, aged thirty-five, spoke about her husband’s alcohol addiction and temper tantrums. He was even arrested once, but released. The arrest was the precipitating event that got his wife to bring him to a doctor. He sought treatment soon after and has been a regular at the hospital for almost two years. He is under medication now and his wife says he has been ‘under control’.

Sofia, aged thirty-one, opted for an abortion after two children. She had fits while at the hospital and was unconscious ‘for a long time’, according to her mother who was also her primary care giver. She came back home with an abject fear of death and immense anxiety about who will look after her children. Sofia also missed her period once and started to get anxious about a possible pregnancy and having to go for another abortion. She sought medical help and found out she was not pregnant. Her mother has moved in
with her to look after her and grandchildren. Sofia’s husband and extended family as well as neighbours have repeatedly told her she is suffering for having aborted a foetus, adding to her guilt. While describing Sofia’s physical complaints apart from her mental anxieties, her mother also said she herself is ‘always stressed’ and her ‘blood pressure is perennially high’.

Ranjana is thirty-two and her father, whom I interviewed, seventy-five. Ranjana is constantly anxious, in tension, restless, irritable and does not want to stay at home. Her father finds it difficult to contain her and said he is too tired to chase after her all the time. Ranjana has been on medication for around five years. In between, since she ‘was completely well’, she stopped her medication on her own, without consulting her doctor. She relapsed and was back at the hospital. When I asked her father, what causes mental disorder, he appeared to be truly confounded and expressed ignorance. He finds it difficult to look after his daughter given her intense behavioural problems, especially at an age when he should be looked after by a child and not the other way round.

James is fifty-one and the primary caregiver; he looks after his wife Anna. Anna was described as violent, aggressive, and as talking to herself all the time and has seen several ups and downs through her illness. James said ‘she was normal’ when they got married. She has undergone electro-convulsive therapy or ‘shock treatment’ and has done the rounds of several hospitals and psychiatrists in the city. James was perplexed and wondered why his wife is the way she is despite ‘doing so much’. She has periods of ‘normality’, but it does not last, said James. He does not know why it started and when it will end.

Narayan looks after his brother-in-law, who is an alcoholic. He often behaves aggressively, is always tense and does not treat Narayan’s sister well. At their wits end, they brought him to a psychiatrist and the medication has helped. Narayan’s sister, he said believes her husband is the victim of black magic and that is why he is suffering so immensely.

Zamil Khan is sixty-two and has been looking after his wife Noor, fifty-five years of age. She has hydrophobia, claustrophobia and what they term ghabrahat (fear) a term used commonly during the interviews. She also has a weight problem and finds it difficult to walk. They live in a small room as a part of a tenement and her claustrophobia makes it difficult for them to stay indoors. Taking a bath is also a hugely anxiety-ridden task because of her fear of water. Her husband has changed doctors several times and is now
seeking help from a quasi-government hospital because of the cost implications. He said ‘the medicines they give us work’ and so he ‘believes in the doctors’.

Rajan’s sister lives in the village, has three children but is unable to look after them or her husband. He brought her to the city to seek treatment because he believed it is more scientific here, rather than in the village, ridden with fear and superstition about her condition. Rajan used the term ghabrahat (fear) to describe the latter. She lives in a joint family in the village and is always overworked and tense. She comes to visit her brother in the city and that is the only time she is able to get some rest. Her fears and anxiety had gotten progressively worse and Rajan finally brought her to the hospital to seek help.

Sujatha is thirty-two and has been undergoing treatment for tuberculosis at the same hospital where I conducted my interviews for a few months. She was extremely anxious and restless and her sisters who had brought her to the hospital had to seek help from one of the resident junior doctors to calm her down while they waited their turn to meet a psychiatrist. She had become increasingly ‘hopeless, almost suicidal’, and her two sisters brought her to the psychiatrist. Sujatha is constantly anxious and believes that she will not recover from tuberculosis. Her sisters were very worried about her and tried to convince her otherwise. Finally, they all went in to meet the senior psychiatrist who along with two other doctors tried to convince her to continue to take her medications and witness her recovery. Sujatha did not seem convinced and said as much to her sisters after they came out of the consultation. Her younger sister was in tears and said ‘nothing works’, expressing despair and hopelessness.

Sashikant came with his fifteen-year-old nephew and nephew’s mother, Sashikant’s sister. His nephew, Aman, has been ‘fearful’ for six months. He has consequently refused to go to school or study. He does not want to step out of the house at all. His uncle works at the local municipal corporation and finds it difficult to take leave to bring his nephew to see the doctor as his livelihood suffers. His mother is always tense about him and her health suffers too. Sashikant has taken on the care giver’s role for both his nephew as well as Sashikant’s sister who otherwise looks after her son.

Perizaad has looked after her brother-in-law Percy for years. His siblings, except Perizaad’s husband, have disowned him. Percy suffers from depression; he is suspicious, irritable and cranky, and he picks fights with his family. Perizaad said it was ‘a chore’ to look after him all those years. They took him to several psychiatrists and had a few rather negative experiences as well. One included going to a prominent psychiatrist in the city who recommended that Percy be put in an institution located far off the city limits. The
psychiatrist said it will do him ‘good’, so they agreed. They did not hear from him for months. They were not allowed to go meet him either. They were told the time and space away from the family will benefit Percy. After months, Perizaad decided to go check on him with her husband, and was able to meet him for a few minutes. The meeting was long enough for Percy to tell them that he desperately wanted to go home and that he was not being treated well. The attendants refused to allow him to go home in the absence of the psychiatrist. At their wits end, Perizaad and her husband fled with Percy, and literally ran away from the institution. Her brother-in-law’s condition has deteriorated since.

Girish is thirty-eight and has been diagnosed as a schizophrenic. He has a doctoral degree in mathematics from one of the best institutions in the country. Girish, however, has been unemployed for over ten years. He is unable to hold a job, is too stressed about travelling and too afraid to even hold tutions in his own home for school children. His parents have looked after him since his problems started sometime in the 1980s when he was a teenager. His mother said, Girish loves mathematics and being alone, and that has allowed him to do really well as a student of mathematics. His medicines have helped. Girish has become more social and helps his mother with household chores. Job interviews trigger off anxiety attacks and he also goes through cycles of depression and mania. He has also undergone several rounds of shock therapy.

Anita is thirty-six and hers was one of the three interviews I did at a care giver’s home. She lives in a two-room small apartment with her parents and brother in a middle-class area of Mumbai. Her father is a retired bank employee. Anita went to one of the best colleges in Mumbai. When she was eighteen, she went for a party and came back ‘very afraid, tense and nervous’. Her parents do not know what happened at the party but remember it as the event that marked the beginning of her problems, and theirs. Anita refused to say anything and they stopped asking after a point. It has been eighteen years since and they still struggle to lead her from illness to wellness. She has done the rounds of not just several psychiatrists in the city but an adjoining city as well. She has been admitted innumerable times and has undergone electro-convulsive therapy. She developed hormone imbalance, facial hair and insomnia as side effects of the drugs she was on. Her neurologist said, she has no brain damage and that all of her problems are ‘psychological’. Her mother related how she has run away from home several times, so much so that her parents stopped worrying and looking for her after the first few times. She usually finds her way back home and there have also been instances when the police
have dropped her home as well. She remembers her phone number and that, her parents say, has been the saving grace.

Anita’s mother is reed thin to the point of being emaciated and walked with a pronounced limp, with her back arched painfully even as the brace she wore around her back and stomach made it difficult for her to sit still for more than a few minutes. She said poignantly, ‘I broke my back looking after my daughter’. She had actually fallen and damaged her spine. Anita’s father looked tired but had a sense of humour and laughed and said, he had no money now to look after his daughter’s needs. They were both worried about their increasing age and were tense about who would look after Anita in the long run. They also have a son, Anita’s brother who has similar problems. He has been under medication but was described as well. He was visiting relatives in their village when I had gone. They seemed happy that Anita was responsible and helped around the house and did most of the chores. Her mother asked her to make mint tea and was really proud that Anita not just brought the tea but also asked me if I would like snacks along side. They are struggling to make ends meet what with the endless treatment and medical expenses that they said ‘don’t end’; but they said relatives have been kind and someone or the other also sends money occasionally.

Mohan is now thirty-eight years old. He passed his tenth standard exams well, but while studying in the eleventh standard he was ragged by some students and developed behavioural problems. He did ‘not talk or take a bath for days’. He was diagnosed with schizophrenia and has been on medication for years. His mother who is seventy-three is his primary care taker. Mohan is also looked after by his brother and father. Mohan’s mother said Mohan ‘looks after himself and does everything very well’ but ‘cannot sustain any work.’ He only ‘helps around the house now’. She was a State Government employee but she had four boys to raise. She says she ‘feels blessed’ because Mohan has ‘never misbehaved but is good to everyone’. Mohan’s extended family has been ‘very supportive and everyone helps to look after him’.

Yezizaad’s father is seventy-four and is one of his primary caregivers. Yezizaad was in a boarding school in a near-by state and, while there, ‘suffered several set-backs’. His parents were contacted and he was given some ‘guidance’. Yezizaad was nervous, fearful and failed his twelfth standard examination ‘miserably’. This affected him deeply and he never quite recovered. Yezizaad is now thirty-five-years old and a ‘recovering schizophrenic’, said his father, an architect of some repute in the city. Yezizaad eventually did pass his twelfth standard examination and even joined a course to study architecture
like his father. But, after three months, he quit the course and joined a film-making course instead. Yezizaad did well here, passed and even started assisting a prominent film maker in Mumbai. He could not sustain this job and quit; took to drugs and started smoking. He was diagnosed with depression as well. Yezizaad has been taken to innumerable psychiatrists and undergone several rehab stints. He is currently not in rehab and when this interview took place, Yezizaad had not been home for three days, much to his father’s anxiety.

Sutlej Zain is thirty-two and currently enrolled as a Ph. D student at a university in Germany. Her family lives in Delhi. She is married and lives in Mumbai otherwise. Sutlej’s mother has been diagnosed with depression. Sutlej’s elder sister used to live in the United States but returned to India, after spending years there and working, when she lost her job and along with that, health insurance. Sutlej’s elder sister was diagnosed with bi-polar disorder several years ago. She was able to function well with medicine, but after returning to India refuses to see a psychiatrist because ‘she is too smart and knows too much about her own condition’, and also ‘does not trust anyone here’. While Sutlej lives in Mumbai, she is often in Delhi looking after her family. Her father had a stroke last year and requires a full-time nurse to look after him while he slowly recovers. Sutlej says she ‘is near break down’ herself, dealing with her mother who often has ‘intense anxiety attacks’, during which she seeks that, her elder daughter Nirmal look after her. Her mother experiences intense body pain and exhaustion during such attacks and usually requires sedatives to calm her down. Nirmal does not usually respond as she herself struggles with her own affliction. While Sutlej looks after her mother and helps her, her mother does not remember anything after an anxiety attack and believes that Nirmal is the one helping her recover. Sutlej even tried to shift her mother to Mumbai to live with her and sought the help of a psychologist. But the arrangement did not last and she was back in Delhi with her mother in less than a fortnight. Sutlej has to look after the day-to-day work in their Delhi house like paying bills and buying groceries. Her mother and sister often forget and are not always able to carry out simple tasks around the house. The financial, psychological, social and medical burden of Sutlej’s caregiving role has been an immensely debilitating experience for her and continues to be so.

The experience of mental illness was truly confounding for the caregivers. They all found that it was also immensely draining in every sense; physical, mental, emotional and psychological. Having to experience and live through a close family member’s chronic mental illness was reported to be immensely difficult and stressful. Lack of support
systems made it worse for the family members. Most of the caregivers I interviewed had also been through several rounds of admissions of their wards in hospitals, both private and government. The logistics involved in managing care was also overwhelming. All the caregivers had at least six months of caregiving experience on the lower end and over eighteen years (cf. Anita) if not more on the upper end.

For most caregivers, explaining mental illness was difficult. They were able to describe behaviour that they thought was problematic, but only so much as it manifested in different areas of their lives; like Noor refusing to take a bath because she was afraid of the water, or Anita refusing to stay at home and insisting on wandering the streets. What they were describing were symptoms and signs. But, as to why this happened, most expressed an inability to understand it. Some said it was ‘buri nazar’ (the effects of the evil eye), others said it was due to black magic. Some said it was alcoholism, some had checked for possession as well. Some also invoked such concepts as ‘karma’.

The caregivers all uniformly used socio-cultural dimensions to explain mental disorder; seldom was an organic cause mentioned. Also the problems were then all defined as external, which is behavioural. All the caregivers described their ward’s condition in terms of anxiety, fear, violence, aggression, insomnia, excessive pessimism, suspicion, irritability, too much tension, stress and also being suicidal. The transition from problem behaviour to disease condition was a difficult one for the caregivers. Thus, their trajectory from the popular sector to the professional sector also meant a radical change in the caregiving role. Seeking the help of an elder to talk to who they thought was an errant child was very different from seeking the help of a professional medical doctor who prescribed tests, medications and also shock therapy for the same set of problems. For most caregivers this transition had to be a guided process; from culture to biology, usually aided by the psychiatrists.

I was able to sit through a few consultations between a patient/care giver and the psychiatrist/s depending on the magnitude of the problem. A new patient called for a junior doctor to explain the case history to the Head of the Department who was the senior Professor present. A few cursory questions were directed at the patient, who reported being sad and withdrawn and not being interested in anything. The senior doctor asked him to take an active interest in life, to go out and participate in activities with other people, to go watch a movie and so on. He also told the patient and the care giver that the medicines prescribed would help him do so.
Caregivers once socialised into the bio-medical system expected medicines and tests and injections. For them coming to a psychiatrist meant all these things. They did not really expect ‘just talking’ as a therapeutic tool to help them or their wards. In other words, during the course of negotiating the bio-medical system they use a basic matrix that involves an external – internal – external change trajectory. The problem behaviour is firstly seen as external. Contact with the bio-medical system means that the response to this external problem behaviour targets the internal body mechanisms, that is, even though the problem is behavioural the treatment is medicinal and pharmacological; this, in turn, will bring about external behavioural changes.

A caregiver’s ability to cope depended on a number of factors including the severity of the problem as well as its duration, the kind of support system available, the prognosis or amelioration of the condition among others. Most expressed that medications helped a lot, to keep the problems under control. But very often medicines were not continued, either because it was expensive or because they felt they were well only to find the problem relapse and seek treatment again. Everyone I interviewed said medicines were important and seeking a doctor’s advice equally so.

Some had stopped medications because they were simply unable to afford it. The hospital I went to gives out free medicines to the caregivers who came. The nurse who gave the medicines out told me she was afraid to do so, because the medicines were sometimes strong anti-psychotic drugs and had to be taken at a particular time and a particular dosage. She explained, no matter how much she reiterated both and also wrote it down, medicines were not given regularly or too much was given or not given at all. Monitoring medicine intake was almost impossible.

By and large, the response to mental disorder and bio-medical treatment was marked by ambivalence. Some reported that it worked for their wards, the medication and the shock therapy. Others said it did not always work. Still others said that, because the medication was so expensive, it was impossible to ensure that they be taken lifelong; hence, this was akin to not having the medicines at all. Other factors like location, travel, finance and support systems constantly intervened in the treatment-seeking process and either aided it or not. All these then also become significant factors in the response repertoire of the caregivers.
Responding to Mental Disorder: Seeking Multiple Practitioners/Systems

All the caregivers that I interviewed sought the consultations of a biomedical doctor with the exception of two; they had all sought help from another practitioner who was not a bio-medical doctor or psychiatrist. All had also consulted more than one psychiatrist during the course of the disease. That is, they had sought the help of multiple practitioners within the same system, not necessarily in a contiguous manner but sometimes also simultaneously. Thus, a minor setback saw the caregiver consult a psychiatrist ‘nearby’, but a major breakdown saw them come back to the hospital, even though located far away.

Apart from the modern biomedical system, all with one exception had sought the help of practitioners from another equally prolific system, that is, traditional/folk healers. Two had sought help from a homeopath and everyone else had been to many or, at least one other practitioner from the folk/traditional sector. A number of factors determined who and how the caregivers sought help from, within the latter system.

Consultation with traditional healers often preceded consultation with the popular sector or the caregivers own social/community network. Often a traditional healer is part of the same network easing accessibility. The fact that the healer knows the family makes it easier still. They are able to immediately locate the problem within a larger family context and would have known, to use medical parlance, the patient’s as well as care giver’s case history without having to ask. Rapport with the healer enables that caregivers’ talk freely and not be intimidated. Caregivers thus stated that they regularly consulted a healer at a local temple or mosque, spelling familiarity in more than one aspect; the healer as well as the physical space. Healers are consulted routinely and regularly for all kinds of issues. If the healer is a part of a sacred space frequented by the care giver, there is a relationship and rapport already established. Traditional healers are often associated with a particular religion and also a sacred space. Religious orientation of the healer was, however, not always a consideration. Often it was the popularity or word of mouth that drew a care giver to a healer for help.

The important question is when all the caregivers who were interviewed were uniformly consulting a psychiatrist or accessing the biomedical system, and none of them expressed overt disappointment with the biomedical system or expressly stated that it failed to work, why do they need to seek help from a vastly different system at all? Everyone I interviewed said medicines were not enough and going to a doctor will not always ensure well-being and recovery; prayers and blessings are equally important, if
not more. None of them, however, derided the role of a doctor; they said seeking a doctor’s help is crucial. But success of treatment again depended on what else one is able to do. The caregivers made a clear distinction between the sacred and secular in this context: psychiatry clearly belonging to the latter realm, healers to the former. For them, healing meant accessing both the sacred and the secular realm. In fact, for the caregivers often the sacred over arched the secular. Thus, no amount of *dawa* (medication) will help unless it is accompanied by *dua* (prayers or blessings) was a common response from the caregivers.

Contact with the healers is defined by this basic dichotomy that caregivers made routinely between *dawa* and *dua* and that determined the larger experience of mental disorder and caregiving. This is akin to the previous dichotomy that was mentioned, that between illness and disease. The disease aspect of mental disorder is addressed by *dawa* and the illness aspect is deemed to be addressed by *dua*, or the healer.

What is also significant is that with the psychiatrist the treatment is directed only at the ill person. Unless the caretaker assumes the sick role and reports being unwell in some way, the psychiatrist will not usually include the caregiver or caregivers within their ambit of medical examination. For the healers, this is not so. Often the caregivers sought out the healer not just for their ward, but also for themselves; to deal with their own tensions and stress and anxieties brought on by the process of caregiving. Attaining peace of mind is how most described the results of this interaction.

Sabina, who has been coming to the hospital regularly with her husband and was happy that her husband appeared to be well after taking his medications regularly and undergoing treatment for alcoholism (and had joined work again), credited his recovery to not just the doctors, but to her repeated visits to the local temple.

Similarly, Sofia’s mother has taken her to the famous Reay road *dargah* (shrine) in Mumbai, well known for its healing work, especially with regard to mental disorder. Sofia’s mother took her there regularly and she was offered blessed water to drink as well as given a *tabeez* (amulet) to wear. Sofia’s mother reads the Quran regularly, does her *namaz* (prayer) and believes in both *dua* (prayer) and *dawa* (medicine). Besides, she also said, ‘*Accha honey se matlab hain*’ (I am only concerned about her [Sofia] getting well), when I asked her why she believed in both. Sofia too believed she has gotten better after her trips to the shrine. For a physical ailment, they go to a doctor, but for a psychological ailment, they said it is better to go to a *maulana* first.
Raisa Sheikh believes that the most important thing is *dua*; everything else, including treatment, follows. James too believes that his trips to his church has helped his wife a lot, and also him in dealing with her condition of constant fear, tension, irritability. The local priest has prayed for his family many times and that has also been very helpful for him. He believes one must do both. Narayan helps his sister look after her husband who is an alcoholic and has been seeking psychiatric treatment too. He said his sister has been to several healers, including a *baba* who cheated them of several thousand rupees but did not help. The amulet did not work either. He is sceptical and said the hospital is a better place. His sister, however, continues to seek help from healers and also believes that black magic has a role to play in her husband’s illness. Narayan said emphatically that he only believed in doctors. His sister, he said, despite the negative experience, continues to seek help from healers.

Zamil has been living with his wife’s various phobias as well as her constant sense of ‘*ghabrahat*’ or free-floating anxiety and fear for several years. They too have been to more than one healer for help, apart from the numerous doctors and hospitals. Zamil has also taken her to a healer who checked if her condition was due to an errant *bhoot-praet* (ghost or spirit). The healer said, it is not, and suggested that she continue to seek treatment from a modern doctor. He also said, if it was a problem caused by possession, he would be able to help. ‘*Dua asar karegi*’ (prayers will help in this case), he said. Zamil went to this particular healer despite being cheated by another healer of more than twenty thousand rupees. He believes that true healers do not charge money for their healing work and he, therefore, seeks assistance from them. He said it is just a matter of finding the right healer, expressing confidence in the larger system and not necessarily a practitioner. Because the element of faith in the system is so strong, caregivers are willing to forgive and forget the occasional black sheep encountered in the form of a charlatan or a fake.

Nilesh has been looking after his mother for years now. She has an obsessive compulsive disorder and is constantly irritable and angry and also has a chronic skin condition. He says her major problem is the skin condition; it is physical and so it is better to seek help from a doctor. He says going to a healer helps psychologically, but not in real terms. Raja Raman did not share a similar sentiment. He looks after his ailing wife and said in response to seeking help from a healer, ‘*sab karna parta hain*’ (One has to do everything). ‘*Only then a problem is reduced.*’ Besides, he also said, it is important for his peace of mind.
Another reason for seeking help from a healer is because the psychiatric treatment and visiting the hospital is simply too expensive, as stated by Raiz Khan. His daughter lost three children, one after the other, and that resulted in tension, stress and depression. While he realises that medicines are important, seeking help from a *maulana* is at least an accessible option and one that may or may not yield results.

Fatima too has taken her father to the Reay road *dargah* apart from coming to the hospital regularly and she believes that right then neither was helping. The shock treatment her father was made to undergo did not help any more than the prayers and amulets. She said she would continue doing both anyway. One needs to have faith was her observation. Persistence will yield favourable results sooner or later.

Raj Ahmed believes that the blessed water and amulet that a *maulana* gave his wife has helped to control her fits of aggression and violence. So, he said, he has seen positive results of doing both medicine and healing. Laxman disagrees and says nothing has helped. His ward was diagnosed with schizophrenia. He said, it is severe and nothing has helped, expressing deep despair. Sashikant’s sister goes to various healers for her fifteen-year-old son Aman, but he is more sceptical and dissuades her. She continues to seek help nonetheless. Babita, who looks after her daughter, believes firmly that one must do both; there will be no peace otherwise, she said. The strength one derives from it is more than what a doctor can give, but the fact is that doctors are also necessary. Babita put it succinctly when she said, ‘*God does not talk back to you. Doctors do.*’ Poverty and ill health has taken a toll on her too and she expressed doubt about how much longer she would be able to continue with her caregiving role.

Girish’s mother has reconciled herself to her son’s inability to work despite having a doctoral degree in mathematics. She too has ‘*done it all*’ in all the years that her son has been unwell. She is still hopeful and said, seeking help from a ‘*sant*’ has given her ‘*peace and strength to help and look after her son and it has also helped him*. Girish, in fact, also attends regular *vipassana* (a kind of meditation) courses and does chanting, which he really enjoys. She too believes all of it is important and helpful.

Anita’s mother too expressed a similar opinion. She and her husband too have seen it all and done it all for Anita, in the eighteen years that she has lived with her illness. They have spent nine months taking her to the Reay road shrine every Thursday to be blessed and prayed upon. They have been to a popular healing church and met with the priest there and attended *satsangs* (religious meetings). They have also been to innumerable temples and met healers of every hue. Anita is their daughter and they said they will do
everything to see her get better. Living with Anita as well as their son, who also has issues with mental disorder, has been an immensely draining experience for their parents. They see their life situation as a result of misfortune, one they term ‘Shani ka dosh’ or a flaw or defect brought on by Shani (Saturn), believed to be one of nine primary celestial beings, and one they need to accept with grace and deal with the best they can. This understanding came from interacting with a sant (literally a ‘true’ person, a wise person, also a healer). Sacred threads were given to Anita to wear which she did. A psychiatrist asked them ‘to take it all off’; they refused. Anita’s parents have also offered pooja to propitiate the gods that rule the nine planets, as Anita’s condition was described to be the result of planetary misalignments. They were also asked to donate food to the poor, to remove and balance out some of the dosh or flaws. A church priest was also consulted who prayed for them and they offered candles there. Japas (chanting), yoga, pranayam (breathing exercise) were all familiar terms for them. At one point, Anita’s mother fell and broke her back and her father had two near fatal accidents, one of which involved being hit by a train and the other a road accident, all in the midst of Anita’s and her brother’s on-going battle with mental illness. Fed up, Anita’s mother asked god to ‘fix’ her or ‘kill’ her once and for all. She said, ‘bhagwan ki meherbani’, god fixed her. She succinctly described her coping skills and strategy and said ‘mujhe vishwaas tha’ (I had faith).

This element of ‘faith’ is a significant and powerful coping skill. It enables the caregivers to cope with otherwise extreme levels of stress due to the nature of mental disorder and its concomitant complexities in social, psychological, financial terms. To be able to cope with such a situation wherein not only must the care giver actively look after an ill person, but do so in a sustained manner, the resources are drawn from multiple sources. Within this framework, the role of the healers and the sacred becomes paramount. The need is so urgent that charlatans and fakes are also overlooked; it fails to deter a caregiver from seeking them out. Modern biomedicine and psychiatry do not suffice because they are not inclusive of the caregivers unlike systems of healing and healers. Where the entire family is seen as a cosmological unit, whose life situations are deemed to be conditioned by factors not always under the control of the people involved, like planetary positions, or possession, or suffering the ill effects of black magic, effects of ‘karmic’ conditions attributed to deeds of past lives and so on. More importantly, there is always something to be done to alter these conditions. And that is why caregivers find this system so appealing and that is also why it is sustainable. As Anita’s mother said, ‘madat milti hain’ (help is given/received).
Some of the caregivers while having gone to a healer as much as a psychiatrist also expressed discontent. Shrikant’s mother also did a lot of ‘pooja/paath’ (offerings to god/and reading from sacred texts) for various gods and she found it very expensive; Srikant has worn amulets and sacred threads, but she said, they did not really help. ‘Only doctors will help.’ It has been particularly difficult for her to look after Shrikant. Once a month she goes to a government hospital to collect his medication. It has been ten years since he has been on them, and she is finding them increasingly expensive. Shrikant also picks up fights and continues to have behavioural problems. In the face of such trials and tribulations, Shrikant’s mother does not see hope in any particular system.

Mohan’s mother too did her share of offering prayers and visiting temples across the city. But the fact that she had three other children to raise, apart from looking after Mohan and working as a state government employee simply left her too little time to do more. But Mohan, she says has always been inclined towards the sacred. So, he would go meet healers on his own apart from going to temples and wearing sacred threads of ‘every colour’. Mohan also goes to a nearby temple every day, and he is doing okay. ‘God is necessary’, says Mohan’s mother. ‘Dua bhi karna hain’ (prayers have to be done too). The fact that she has support from her extended family and that Mohan is functional are all due to ‘god’s blessings’. She said, ‘dua and dawa dono zaroori hain’ (both prayers and medicines are necessary), she cannot choose one.

Similarly, Yezizaad’s father goes to the local Parsi Fire Temple every day and consults the priest regularly about Yezizaad. But he also says his going to the temple will not help; Yezizaad has to go. He has stopped praying for him, because Yezizaad needs to pray for himself. But his wife and Yezizaad’s mother ‘tries everything’. While he endorses both dua and dawa, he also believes in karma (sum of person’s actions including in past lives). So, he says, Yezizaad ‘needs to figure it out for himself’ but ‘sincerity is important’. Yezizaad is not ‘doing anything’, but his father says, going to the Fire Temple helps him.

The religious orientation of the healer does not appear to be a significant factor in determining choices. Although the tendency is for everyone to seek help first from a healer familiar to them, factors like physical proximity or reputation of a healer or healing shrine is also a consideration. Muslim caregivers interviewed did not state going to a temple priest to seek help. But caregivers following other religions did say they have been to a shrine or consulted a maulana. For instance, the Reay road shrine in Mumbai sees a huge number of people from all religious backgrounds frequenting it.
Caregivers also stated that, if not they, a family member had been to a healer to seek help for a relative living with mental illness. The severity of the illness appeared to be a factor in determining how the healers and healing work was perceived. In the severe cases or chronic cases, relatives and close family members expressed despair and a lack of faith in medicines as well as healers. How effectively healing is perceived to work depends on the level and intensity of the problem as well as how it is seen by the caregivers. If it is deemed to be possession, then they see a way out with the help of the maulana or a priest who will exorcise the ghost or spirit. The absence of possession state puts it neatly within the ambit of medicine and psychiatry and there they believe it is more the doctors and medicines that help. The prayers and blessings from a healer will ensure that treatment is successful and smooth.

The fact that medications kept their wards functional and functioning, able to carry on day-to-day activities see them returning to psychiatry even after gaps. Caregivers use the external – internal – external matrix to view psychiatry and also to judge efficacy. Within this matrix, external behaviour that is problematic is deemed to undergo changes with the help of medications or shock therapy that bring about internal changes within the body and manifest in changes in external behaviour again. Their expectations from psychiatry are thus very specific. More often than not, the experience is so overwhelming that it is difficult for a family member to make sense of it. That is, their cognitive schema does not hold a conceptual frame within which to place mental disorder. This frame, to some extent, is provided by modern medicine, but it is also culturally alien; it has to be supplemented by another system. Often this frame is provided in the realm of the sacred.

One of the most important observations that came out of all the interviews was that people actively seek the help of healers apart from a doctor, and do so simultaneously, while their wards undergo bio-medical treatment. They may or may not believe that this works, but do not stop nonetheless. People’s perceptions about mental illness does affect who they seek help from to some extent, but the ubiquity of the modern doctor in a city like Mumbai ensures that they are not entirely disconnected from it. Hence, there will be instances where a maulana or a priest will refer a case to a psychiatrist reflecting an awareness that moves beyond their particular expertise.

The larger understanding of caregivers is that aetiology of mental disorder lies in multiple dimensions: medical/biological/organic as well as socio-cultural/cosmological. One set of practitioners deal with one dimension, that is, psychiatry as the bio-medical system, and healing as the one dealing with the other. Hence, the frequent assertion that
both *dua* and *dawa* are necessary for recovery. Socio-cultural conditioning ensures that the former finds a prominent space in their scheme. Interface is possible precisely because of this distinction. The other important consideration that again facilitates interface is that the element of *dua*, by virtue of being structured as such encompasses *dawa*. Hence, a prayer said before a medical treatment, or even pharmacological intervention will add to the efficacy of the medicine or treatment.

Within a cultural space that allows multiple options for health-seeking behaviour as well as a cultural orientation that actively supports and encourages it, it is not alien to seek such help. In fact, modern medicine (and psychiatry) comes across as more alien to the caregivers and people living with mental illness. More than one care giver expressed discomfort about approaching a psychiatrist, but also at the same time reposed confidence in the system. There was thus basically an ambivalence expressed towards modern medicine.

However, parallels between both systems were also pointed out; both called for one to ‘have faith’ for it to work; both had good and bad practitioners; both may or may not work; both are influential systems and have the ability to draw people to them despite the occasional negative experience; and, finally, both are here to stay.

The need to see their family member ‘get better’ is the major and most important motivating factor for almost all caregivers to seek help outside of the medical fraternity. Practitioners have their systems to protect and uphold. Caregivers only want that their family member to recover. Mental disorder, for them, is a day-to-day experience and they live that experience on a daily basis. For the caregiver, this experience is an intricate and complex weave of the disorder with multiple treatment options based on differing systems, combined with their individual coping strategies. For most, mental disorder is a long-term phenomenon that they have to deal with. Within this understanding, two concepts stand out and call for further examination that is, *dua* and *dawa*. At one level, these concepts epitomise the two separate epistemologies followed by two separate systems of health care. But caregivers are able to align them together despite their contradictions. How is this so?

The experience of mental disorder for the caregivers can be viewed from a phenomenological lens. The ability to cope with mental disorder is mediated by the meaning that caregivers construct of the phenomenon of mental disorder. This is socio-culturally determined for them to some extent; it is also a dynamic construct because they negotiate its meaning while living with it and experiencing it through their caregiving
role. The meaning is thus modified through an interpretive process. *Dua* and *dawa* are essential components of this process. To use a term from phenomenology, *dua* and *dawa* become ‘indexical terms’ for caregivers; these concepts at one level organise the experience of mental disorder for them, it objectivates it for them, enabling them to deal and cope with it.

*Dua* and *dawa* are a part of what symbolic interactionists term, the ‘schemata of interpretation’ that enable individuals to ‘locate, perceive, identify, and label’ occurrences within their life space and world at large’ (Ritzer 1996: 359). The frame of *dua* and *dawa* renders events and occurrences meaningful, in the context of mental disorder and functions to ‘organise experience and guide action, whether individual or collective’ (ibid.). They become a part of the caregivers ‘life world’ (*lebenswelt*). *Dua* and *dawa* are located in a world of meaning that is socially, culturally and historically constituted. As much as caregivers find mental disorder an immensely difficult experience, these two concepts help to give it meaning. Their life world will thus contain *dua* as much as *dawa* and is inherent to their reality. And their sole motivation to see the sick person ‘get better’ becomes the cohesive force that binds these two concepts together despite disparities.

What is interesting is that, while practitioners see their system as sufficient to deal with mental disorder, caregivers use both to not just define, but do so for the sole purpose of enabling them to cope with their caregiving responsibilities and, more importantly, enable a shift for the sick person from illness to wellness.

**Conclusion**

To conclude, the caregivers cognitive package includes both *dua* and *dawa*; idiosyncratic as it might appear to be on the outside, it constitutes a powerful healing and coping strategy for the caregivers and constitutes and incorporates viable treatment option for people living with mental disorder. Caregivers, at the end of the day, are more concerned about treatment possibilities and not driven by scholastic or disciplinary concerns or even systemic restraints. This might also explain why religion is not a factor for all caregivers with regards to choosing a healer. Similarly, education does not appear to be a consideration either for this set of caregivers. An architect, a bank employee, a trader all consulted with healers. It is to be noted that caregivers did report negative experiences with healers; negative experience was also reported with regards to a psychiatrist. Despite these setbacks, they all continued to avail of both systems.
Caregivers essentially deal with an illness experience which is a much wider repertoire of experiences and surpass the disease condition. Their treatment choices are also connected to their perceptions about mental disorder, including aetiology. They not only deal with a condition termed mental disorder, whatever specific condition that might be, they also often deal with a range of physical ailments for the same person, apart from their own set of health issues. Caregivers access different systems simultaneously without conflict, because no one system is able to help them cope with such a situation, very simply put. They inadvertently bridge epistemologies while doing so.

1 Diagnosed in accordance with the Diagnostic and Statistical Manual (DSM), currently reviewed for the fifth time and the International Classification of Diseases (ICD).
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<td>3</td>
<td>F 60s Mo</td>
<td>Fa</td>
<td>Irritability, suspicion, tension, insomnia, anger, stress</td>
<td>–</td>
<td>Mosque, Maulana</td>
</tr>
<tr>
<td>4</td>
<td>M 75 Fa</td>
<td>–</td>
<td>Tension, restlessness, irritation</td>
<td>–</td>
<td>Church</td>
</tr>
<tr>
<td>5</td>
<td>F 37 Wi</td>
<td>–</td>
<td>Addiction, talks to self</td>
<td>Alcoholism</td>
<td>Mosque</td>
</tr>
<tr>
<td>6</td>
<td>M 51 Hu</td>
<td>–</td>
<td>Aggressive, talks to self, trembling, leaves home</td>
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<tr>
<td>7</td>
<td>M 30s Br-in-la Wi*</td>
<td>Tense, aggression, violence.</td>
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<tr>
<td>8</td>
<td>M 62 Hu</td>
<td>–</td>
<td>Fear, hydrophobia, claustrophobia</td>
<td>–</td>
<td>Mosques, more than one Baba</td>
</tr>
<tr>
<td>9</td>
<td>M 40s Br</td>
<td>Mo-in-la*</td>
<td>Negligence, carelessness, tension, stress</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>10</td>
<td>M 20s So</td>
<td>Hu*</td>
<td>Irritation, anger, insomnia</td>
<td>OCD</td>
<td>Temple</td>
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<tr>
<td>11</td>
<td>F 30s Wi</td>
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<td>Anger, tension</td>
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</tr>
<tr>
<td>12</td>
<td>M 60 Da</td>
<td>Parents*</td>
<td>Sadness, insomnia, tension, stress</td>
<td>Depression</td>
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</tr>
<tr>
<td>13</td>
<td>F 29 Da</td>
<td>Wi*</td>
<td>Trembling</td>
<td>–</td>
<td>Mosque, Maulana, Healing Shrine</td>
</tr>
<tr>
<td>14</td>
<td>F 30s Si</td>
<td>Sis</td>
<td>Anxiety, insomnia</td>
<td>TB, Depression</td>
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</tr>
<tr>
<td>15</td>
<td>M 40s Hu</td>
<td>Mo-in-la</td>
<td>Irritation, fear, paranoia</td>
<td>Schizophrenia</td>
<td>Maulana, mosque</td>
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<tr>
<td>16</td>
<td>M 50s Hu</td>
<td>–</td>
<td>Dimaag ka problem (problem of the mind)</td>
<td>Schizophrenia</td>
<td>Never been to anyone</td>
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<tr>
<td>17</td>
<td>M 40s Uncle Mo*</td>
<td>Fear</td>
<td>Anxiety</td>
<td>Temple</td>
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<tr>
<td>18</td>
<td>M 20s Br</td>
<td>Mo*</td>
<td>Fear, suspicion, hearing voices, suicidal tendency</td>
<td>Psychosis</td>
<td>Temple, rituals</td>
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<tr>
<td>19</td>
<td>M 40s Hu</td>
<td>In-laws</td>
<td>Tension, hearing voices, talking to self</td>
<td>–</td>
<td>Mosque</td>
</tr>
<tr>
<td>20</td>
<td>M 40s Hu</td>
<td>–</td>
<td>Fear, hearing voices, restlessness, suicidal tendency</td>
<td>TB, psychosis</td>
<td>Temple</td>
</tr>
<tr>
<td>21</td>
<td>F 60s Mo</td>
<td>–</td>
<td>Fear, insomnia, fear of death</td>
<td>–</td>
<td>Temple</td>
</tr>
<tr>
<td>22</td>
<td>M 50s Hu</td>
<td>–</td>
<td>Tension, anger, insomnia, irritation</td>
<td>HIV, TB</td>
<td>Temple</td>
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<tr>
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<td>Si</td>
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<td>Hu</td>
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<td>Hu</td>
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<td>Fear</td>
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<td>F</td>
<td>60s</td>
<td>Mo</td>
<td>–</td>
<td>Sadness</td>
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<tr>
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<td>Br</td>
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<td>36</td>
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<td>Si-in-la</td>
<td>Extended family/Siblings</td>
<td>Quiet, irritable, withdrawn</td>
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<td>Withdrawn, tense, talking to self</td>
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<td>74</td>
<td>Fa</td>
<td>Mo</td>
<td>Nervous, fear</td>
</tr>
</tbody>
</table>

*Note: BPD = Bi-Polar Disorder; Br = Brother; Br-in-la = Brother-in-law; Da = Daughter; F = Female; Fa = Father; HIV = Human Immunodeficiency Virus; Hu = Husband; M = Male; Mo = Mother; Mo-in-la = Mother-in-law; OCD = Obsessive Compulsive Disorder; Si = Sister; Si-in-la = Sister-in-law; So = Son; TB = Tuberculosis; Wi = Wife*