CHAPTER II

METHODOLOGY

The literature that was reviewed spanning almost 40 years of caregiving research revealed that caregiving is indeed a challenging task. The presence of schizophrenia and its spectrum disorder is marked by impairment in cognitive, social, interpersonal, behavioural, and affective areas, which affect the overall functioning of the person. In India, as the family is the primary caregiver, it is necessary and desirable that caregivers handle these impairments while supporting the person to adjust to the illness and its impairments, and to realise his/her fullest potential. It is a unique experience for the family members. Literature shows that caregivers experience both positive as well as negative consequences (the latter is commonly termed as burden), and distress. This was discussed at length in the first chapter. The review of literature also revealed that many aspects in the caregivers’ environment have been found to explain burden. The nature of the consequences is determined by the context in which families are situated and the characteristics of the caregiver and the care recipient, and by clinical variables such as history of the illness and adaptation, duration of untreated psychosis, positive and negative symptoms, etc. of the care recipient. However, as mentioned in the previous chapter, literature which has explored caregiving in schizophrenia has been in the quantitative tradition, often revealing contradictory results about the impact of clinical variables on burden. Factors that have shown to be consistently correlated to caregivers’ burden and wellbeing are psychological characteristics such as personality factors like neuroticism, coping skills, etc. Recent literature indicates how caregivers conceptualize their relative’s mental illness and how that could be an important predictor of their distress. This makes caregiving for schizophrenia a different situation within the unique socio-cultural environment of India. The review took stock of the caregiving situation in India. Caregiving has always been family centric in India, reducing the chances of homelessness for the mentally ill. However, with the emergence of the nuclear family system, and with women performing multiple roles, caregiving has become very challenging. Thus, it was clear that an in depth study of the Indian caregivers would have to reflect these unique caregiving conditions of India.
Examination of the literature in social and community psychology has revealed a recent focus on illness understanding and its importance in determining the reactions to mental illness. The literature review revealed works of Yarrow et al (1955), Klienman (1988), Leimkuhler and Madger, and Boyraz et al (2011), who have shown that perceptions in caregiving are influenced by various cultural, social, medical, personal and clinical variables. Few qualitative or quantitative studies have been conducted to explore the process of caregivers’ illness conceptualization. A number of models that attempt to understand the care recipient’s understanding of the illness are being applied on caregivers too, such as the CSM model by Leventhal et al (2003). A detailed study of the model discussed in the previous chapter revealed that the theorist came up with 7 primary constructs of illness understanding, namely, illness identity, understanding of its cause, its consequences, its course, it’s control/care, and the timeline of the illness and coherence.

What was also examined in the review of literature was how authors have applied this in caregiver research in mental illness. The review revealed the major application of this work on how these constructs impact caregivers’ emotions and behaviours. Further analysis of models of other theorists revealed that more constructs were proposed. The C-SHIP model by (Mischelle & Shoda 1995) although very robust in explaining how one could process health risk related information, has never been applied to caregivers’ understanding of mental illness. Another set of studies that adopted an approach to learn about indigenous systems of healing and explanatory models to arrive at an understanding of distress is closer to the care recipient’s experiences, which are common to specific cultural groups, were discussed in the previous chapter under the section on Explanatory Models. The section primarily elaborated on Kleinman’s (1980) perspective and characteristics of explanatory models. The tools for understanding caregiver conceptualizations based on the explanatory models were reviewed. However, the criticism by Bhui and Bugra (2002) seems valid, that this method assumes that the ranges of beliefs that are of interest are largely known, and that the constructs presented in the questions are familiar to people from different cultural and linguistic groups. This perspective was found to be adopted in a few studies in India. Kleinman’s model (1980) has been used as a basis for some qualitative studies in India. These studies have focussed primarily on capturing caregiver attributions and beliefs, which have been shown to be complex, dynamic and sometimes contradictory (Thara et. al 1998).
Past research has pointed towards the fact that caregivers’ understanding of the care recipient’s mental illness is one of the important factors effecting the caregiver’s reaction to mental illness in the family, which also has a cascading effect on the care recipient’s wellbeing. Despite these findings, few studies have looked into caregivers’ understanding of their relative’s mental illness exhaustively. Most studies, at most have only paid a cursory glance on the subject. Majority of the studies conducted are available in international literature, with very few studies emerging from the sub-continent. The few studies which have been published on the subject, both from and outside India, have focussed primarily on the beliefs of caregivers, especially their attributions of causality and controllability of the illness (Barrowclough et.al 1996, Srinivasan & Thara 2001) Some of these studies have extended their focus to also include the impact of these illness conceptualizations on the management of the illness and wellbeing (Barraowclough et.al 1996). However, the scope of these studies is narrow as they focus primarily on the content of the caregiver’s definition of meaning, largely ignoring the processes that underlie the construction of the conceptualization and how it impacts the people’s illness understanding. This could be primarily due to the fact that most studies have been based on models generated for the care recipient, with the exception of the Explanatory model by (Kleinman1978).

Kleinman’s explanatory model treats healthcare as a cultural system. The family’s understanding of care recipient’s illness is described in the cultural subsystems of healthcare. The focus of this theory lies in the interactions between the three sub sectors in the healthcare system i.e. of folk, popular, and professional arena. Family lies in the popular sector, along with the care recipient himself, and the larger community. Kleinman purported that all sectors explain the condition with the five issues: aetiology, course, onset of symptom, pathophysiology, and treatment. With the onslaught of the bio-medical disease model in developing nations, there are major changes in the understanding in the popular culture, which needs to be studied in detail (Kleinman 1978). An example of this can be seen in the development of the concept ‘trouble’. It relates in the popular culture to troubles related to the sickness and to management. This example underscores the fact that one has to elicit concepts developing in the various players in the healthcare system in different cultures. Thus, this underpins the need to have more such qualitative studies in various cultures, to elucidate this phenomenon. Elucidating the processes of illness conceptualization is of significance if we have to understand caregiving in all its nuances.
Thus, there is need for theoretical formulations and models that integrate the variety of aspects of the caregivers’ understanding of the care recipient’s illness. Literature also points towards the fact that the caregivers’ illness conceptualizations could impinge upon various aspects of caregiving, such as approaches to caregiving, and emotional and behavioural reactions. It would be worthwhile to explore these aspects of caregiving to enable better management of caregivers’ and care recipient’s distress. To this effect, it would be helpful to examine the association between the illness understanding of caregivers and the related emotions. Thus, caregivers’ conceptualizations that give rise to maladaptive emotions, e.g. guilt, and behaviours such as over protectiveness can be addressed to avoid such emotions. As mentioned earlier, India offers a unique socio-cultural set up that influences the health system. Therefore, the current study aimed to explore the illness conceptualization of schizophrenia by caregivers, with special reference to the socio cultural context of the caregiver.

The present chapter first presents the rationale of the study, emanating both from substantive and methodological terms that the study attempts to address. This leads to a statement of the objectives of the study and the research questions. In the next section, the conceptualizations of important areas of study have been explained. The following section presents the research design, and the choice of the research sites, the participants, and the methods and strategies used for data collection have been detailed. This is followed by an articulation of the research paradigm. The last section describes the procedures I adopted to gain access to the research sites, collect the data, and analyse the data.

**Purpose of the Study**

The above discussion brings forth a few important points. The literature is sparse with reference to caregivers’ understanding of mental illness, both internationally as well as from the Indian subcontinent. Studies that have emerged in the area of caregivers’ understanding of mental illness, have primarily borrowed and applied models that have initially been developed either for physical illnesses or for care recipients. However, while adapting from these models, few studies have used these pre conceived categories on care recipients’ and caregivers’ to elicit relevant conceptualizations. This runs the risk of missing out on conceptualizations indigenous to a particular sample under study. India offers a unique socio-cultural environment to caregivers. It would be worthwhile to include the socio-cultural influences in any study that aims to understand
the caregivers’ conceptualizations. This will enable a better understanding of the origin and development of caregiver conceptualizations. Thus, a holistic understanding of caregiver conceptualization would require a complete integration of aspects of the caregivers’ environment that facilitate their understanding of the illness, their conceptualizations, and the impact those conceptualizations have on caregivers’ emotions and behaviours. Based on the above-mentioned dimensions, the purpose of the study was arrived at. The focus of the study is to understand how the caregivers define their relative’s mental illness. I wanted to understand the construction of this definition of illness by the caregivers’. I also wanted to explore newer themes and processes that might appear in caregiver interviews, and was interested in exploring the association between the caregivers’ conceptualizations and their emotions. Thus, the need to understand the psychological processes in caregivers’ illness conceptualizations, their own feelings and rationale for caregiving decisions guided the present study.

**Objectives**

1) To understand the content of illness conceptualizations through the concepts and constructs that reflect caregivers’ conceptualizations of schizophrenia.

2) To understand the process of illness conceptualization and how this process is contextualised by important influences that emerged through the data.

3) To examine the association between the conceptualizations and emotions experienced by the caregivers.

**Lines of Inquiry**

- Elicit the caregivers’ current conceptualization of their relative’s illness.
- Examine the context and processes that facilitate conceptualization (illness or otherwise).
- Understand their methods to deal with the situation.
- Enquiry into their feelings experienced at that time.
- Capture their emotional and behavioural reactions to their conceptualization.

The lines enquiry was modified during data analysis, when it was realised that the caregiver’s conceptualization of care recipients’ illness was evolving with the changing course of the illness. Therefore, the following points were added in the lines of enquiry:
• Enquiry into the onset of the illness and the actual recognition by the caregiver, of the aberration in the behaviour of the care recipient.
• Understand caregivers’ conceptualization of the illness (if conceptualized as an illness or otherwise) activated at the time of first recognition of aberration in the behaviour of the care recipient.
• In case not conceptualized as an illness, further enquiry into the nature of their alternate conceptualization of the problem.
• Explore the nature of the help sought.
• Enquiry to elicit the degree of integration between the illness and their and the care recipient’s lives.
• Enquiring into the emotional and behavioural reactions of the caregiver during this phase.

Similar lines of enquiry were continued for relapses or any other significant moments identified by the caregiver in the caregiving process.

**Research design**

Grounded theory is a research method that uses a systematic set of procedures to develop an inductively derived theory about a phenomenon (Strauss and Corbin, 1990:24). The inductive method signifies the process by which the theory develops from data or grounded in the data.

Grounded theory’s importance has grown in times of social change and globalization. In these times, the limitations of quantitative methods are clear. Quantitative methods, by definition test hypothesis derived from existing theories, making it redundant in evolving times. Thus, grounded theory becomes crucial to produce novel theories when the older theories fail to explore a phenomenon or are outdated (Bryant and Charmaz 2007). Diverse racial and ethnic backgrounds produce differences in experience, which makes the opportunity to create new theories that incorporate this diversity (Bryant and Charmaz 2007). Grounded theory methods were developed by sociologists Glaser and Strauss (1965:76) collaboration during the 1960s. The positivist approach had eroded the ethnographic traditions in sociology. Empirical methods had dominated research. Positivist methods assumed an unbiased passive observer, the separation of fact and value,
the existence of an external world separate from the scientific observer, and their methods focused on the accumulation of knowledge of this world (Charmaz 2005). The trend was of the theory to guide the research. Challenges of the strong positivist tendency developing in the field of sociology laid the foundation for the development of the grounded theory approach. Glaser and Strauss found the division between theory and research arbitrary, considered qualitative research as precursor to quantitative theory, and refuted beliefs that qualitative methods were unsystematic and that data analysis and collection had to be separated. They rejected the assumption that qualitative data could not generate theory. Glaser and Strauss’ methods emerged based on the research procedures utilised by their predecessors, but were never laid down. Other influences included Strauss’s training rigorous quantitative training which informed their epistemology, and the systematic approach they brought in grounded theory.

Grounded theory methods have application across disciplines (Glaser and Strauss 1967). It is widely applied in research in areas like nursing, education, organizational studies, and evaluation research (Charmaz 2005). Utilization of this theory in psychology is widely recognized. There is an increasing dissatisfaction with existing quantitative methods. The existing methods are found to be missing thinking and discovery, with grounded theory becoming the choice of methodology for areas difficult to access with traditional research methods. Charmaz (2005) recommends grounded theory as a promising method to study development, maintenance, and change of individual and interpersonal processes because it is designed to study processes. Charmaz (2006) recommends the utilization of grounded theory as a bridging method for interpretive and positivist methodology in disciplines like psychology. Since the present study wanted to explore the conceptualizations and dynamism in it, grounded theory was found to be best suited for the purpose.

The elaboration of grounded theory procedures and its application in the study have been discussed in the section on research methods.

The Research Paradigm

The present study was based on a constructivist paradigm, as described in detail by Guba and Lincoln (1995). They elaborated the ontological, epistemological positions, and methodology in constructivism, and explained that constructivism assumes reality to be understood in the form of
multiple, intangible, mental constructs, socially and experientially based, local and specific in nature, and dependent on form and content on individuals and groups holding the constructions. They explained the epistemology to be transactional and subjectivist where reality is really created between the investigator and the object of investigation, during the process of investigation. The methodology recommended to explore individual constructions is dialectical and transactional, that taps the interactions between and among investigators and respondents (Guba and Lincoln 1995).

Kathy Charmaz (2006) explains Grounded theory as having taken two different forms, objectivist and constructivist. The key characteristics of the research strategy employed in the present study conform to the constructivist form of grounded theory.

Constructivist grounded theory lies in the interpretive tradition. Analysis and data is created from the interaction between researcher, participant, and other resources. Objectivist grounded theory resides in the positivist tradition, and thus attends to data as real in and of themselves, and does not attend to the processes of their production. Constructivist grounded theorists, assume that although the goal of the researcher is to represent the views from the insider’s perspective, yet there is a realization it is not possible to replicate the experience of the participants. The researcher’s analysis not only represents the participant’s view, but the researcher’s theorization of the participant’s interpretation and an acknowledgment of the same is represented through the analysis. The theory depends on the researcher’s view, and it does not and cannot stand outside of it (Charmaz 2006). Objectivist grounded theory assumes that reality is objective, can be “discovered” or “unearthed” untouched by the theoretical influences of the researcher. It aims for prediction through systematized procedures that allow for reproducibility, hypotheses testing, and exertion of controls. However, a constructivist grounded theory asserts that “this is correct only to the extent that subjects have comparable experiences and viewers bring similar questions, perspectives, methods and subsequently concepts to analyse those experiences” (Charmaz 2000:524). Thus, in constructivist grounded theory, causality is incomplete and indeterminate; the constructed theory remains open to refinement.

The present study conformed more to the tenets of constructivist grounded theory. My assumptions or lens have already been clarified in the beginning of this chapter. Thus, my theoretical assumptions not only guide the study, but are seen to enhance the study. My interpretations of the data present are also informed from my professional experience as a clinical psychologist. My training and education as a clinical psychologist influences my basic assumptions about behaviour. I align with the psycho-medical model of behaviour. Thus, maladaptive behaviour is always interpreted as a mental health concern and/or mental illness. Although the psycho-medical model provides for the interpretation of abnormal behaviour, my training makes me involve models held by other players in the given context, such as the care recipient himself, the caregiver, and other professionals, in understanding those behaviours. My professional experience, also made me rely
on open ended questioning, empathetic understanding throughout the interview, and supportive counselling to the caregiver after the interview was over.

The analysis in the present study makes it clear that data presents a co-constructed reality between the researcher and the participants. The language used in this thesis makes explicit the subjectivity of the researcher in the use of ‘I’ in the introduction to the thesis, where the overall research agenda and the rationale behind the research is specified, as well as in the procedures of data collection. Data extracts have been presented separately from the interpretations of it, further highlighting the fact that the representations of the reality are only an interpretation of the researcher. Finally, the data is presented, not as evidence for the theory, instead through the use of “I interpret”, the theory is presented as one way of seeing the data. The study aligns itself to constructivist paradigm also because it considers reality as constructed by the respondents and their view of it. Thus, that becomes the focus of the study.

The study aimed to understand illness conceptualisations. These concepts and the framework that guided the study have been explained below. Keeping to the tradition of qualitative inquiry, especially in the grounded their approach, they are only sensitising concepts or frameworks. What the respondents revealed in the interviews would finally help shape the study.

The Conceptual Framework

The Subjective/Active/Process Approach (SAPA)

This present study adopted the conceptual framework similar to an approach discussed by Knafl and Deatrick (1987), called the Subjective/Active/Process Approach (SAPA), that there is no single objective meaning of disability. SAPA, as an approach is a result of Kanfl and Deatrick’s extensive literature review of research undertaken in the field of how families respond to a member's chronic illness or disability. They organised their literature review on Vyose (1975) approach, focussing on following:

1. How the investigator treated the family's definition of the situation,
2. How the investigator conceptualized the family's response to illness,
3. How the investigator designed the research.

Their literature review focussed around these 3 principles, revealed systematic differences across studies with regard to the above three dimensions. The three dimensions are not in-dependent of
one another. They named these different approaches as the Objective/Passive/Outcome/Approach (OPOA) and the Subjective/Active/Process/Approach (SAPA).

Researchers employing the OPOA approach, who focused on the objective meaning of the illness or disability, tended to conceptualize the family's response as passive. Therefore, they directed their research efforts to measuring the impact of having a chronically ill or disabled child on family life. In contrast, SAPA investigators, who focused on the family's subjective definition of the situation, tended to conceptualize the family's response as active, and therefore, attempted to design research which addressed the process of adapting to a child with a chronic illness. Thus, SAPA researchers proposed that studies which have been undertaken with this approach tend to focus more on discovering how families actively manage such situations, and less on measuring outcomes. They tend to be more process oriented, employing a qualitative research design. SAPA conceptualizes families as responding actively to illness situations, and thus, the related research focuses on how families both define and manage illness.

I adopted a similar approach in the present study, and assumed that there is no fixed universal definition of mental illness adopted by the caregivers. Caregivers actively define the mental illness, and this definition is subjective to each one of them. This assumption guided not only the study objectives, but also the methodology. A qualitative research design was found best suited to achieve the in-depth understanding of caregivers’ definition of mental illness. This assumption also guided the construction of the interview schedule. The in-depth interview guide was designed from a neutral perspective, with as few preconceptions as possible, such as ‘caregiving is necessarily a negative experience’, ‘all caregivers face only burden’, ‘caregivers will automatically look for blaming someone (self or other) to explain the illness’, or ‘caregivers necessarily have very well defined expectations about prognosis of their relative’. Open-ended questions with probes were formulated (refer to section on Tools for details).

A Cognitive Model of Emotion

This study aimed to explore the emotional and behavioural reactions associated with illness conceptualization. The assumption underlying this objective emanated from the cognitive model of emotions. This model proposes that cognitions have a significant effect on emotion, although it is also added that this effect is not linear. Appraisals of the encountered situation determine the emotion experienced. Lazarus and Folkman (1984) elaborated on appraisal in the context of the role it plays in the stress appraisal coping theory. They conceptualised appraisal as the process of categorising an encounter and its various facets with respect to its significance in well being. According to them, appraisal is largely evaluative, focus on meaning or significance, and takes
place continuously during waking life. However, appraisal is determined by a number of factors, including personal such as commitments, beliefs (pre-existing notions about reality) about personal control, and existential beliefs (Lazarus & Folkman 1984). Thus, it can be concluded from their study that a number of personal factors of the care recipient, along with situational factors, influence the appraisal process, which in turn influences emotions. Informed by this model, the present study assumed that conceptualizations would be accompanied by emotional experiences and thus was focussed on studying the emotions discussed by caregivers in association to their conceptualizations regarding the care recipients’ condition.

*Conceptualizing Illness Understanding, Emotional Experiences and Behavioural Reactions, and Influences on the Process of Illness Conceptualization*

Exploring the illness conceptualization of the caregiver was the core objective of the present study. The self-regulation model proposed by Leventhal et.al 2003) describes it as cognitive and emotional representations of the illness. In the literature, this is often referred as illness perceptions. Research in the area of illness conceptualization has found the following components of illness representation (Diefenbach & Leventhal 1996):

- **Identity**: The name or label of a threat (e.g., sore throat, arthritis).
- **Timeline**: The threat's believed time trajectory (e.g., acute, chronic, cyclical).
- **Consequences**: The believed consequence of a threat (minor or major).
- **Cause**: The threat's causal mechanism (e.g., hereditary, external, internal).
- **Control/cure**: Whether something can be done to control the threat.
- **Illness coherence**: Whether a person thinks about the threat in a coherent way.

Kreisman and Joy (1973) operationalised their exploration of families’ definition of the care recipients’ illness as families’ explanation of the care recipient who would later get labelled as ‘mentally ill’. It is understood as mental representations of the illness constructed by the caregivers.

Illness conceptualization, in the current study, referred to the caregiver’s thoughts about the event, i.e. care recipient’s illness. Although this concept includes a definition or explanation of the illness, it was not limited to the same. It was understood to include everything that the caregiver thinks about the care recipient’s illness. Thus, the scope of this concept was widened such that all the cognitions related to the illness emerged and could be available for mental health professionals to use to develop their approach more relatable as well as adaptive for caregivers and families. However, caregivers’ understanding of the illness needs to be distinguished from the meaning they make of the experience of illness.
A complicated and poorly defined concept, meaning, is defined with certain accuracy by Baumeister (1991), as a “mental representation of possible relationships among things, events, and relationships.” Meaning making is closely attached with the concept of coping with the catastrophic experience. The meaning that family makes of the experience of the illness pertains to the family’s response that attempts to clarify what appears incomprehensible, managing that which feels out of control, and finding relevance in confusion (Rose 1983).

The current literature dealing with meaning making has limitations because it does not examine all the constructs related to meaning making, leading to inconclusive findings (Park 2010). The meaning making model suggested by Park and Folkman (1997) is based on the basic tenets of meaning making, which include the following:

- **Global meaning.** These are orienting systems which provide cognitive structures to interpret incoming information.
- **Situational meaning.** This refers to meaning in the context of occurrence of a stressful event, which includes assignment of meaning to the event (appraised meaning), determination of discrepancies between the appraised and global meaning, meaning making, meanings made, and adjustment to the event.
- **Appraised meaning of the event.** This includes the assessment of controllability, threat from the event etc.
- **Discrepancies between appraised and global meaning.** This is the determination of the fit or discrepancy between the appraised meaning and their global meaning.
- **The meaning making process.** This aspect discusses the processes during recovering from a stressful event, which reduces the discrepancy between its appraised meaning, and global beliefs and goals.
- **Meanings made.** Meanings made refers to the products of the meaning-making processes, which include the belief of having made sense, reattributions, and causal understanding of the event.
- **Perceptions of growth or positive life changes.** This refers to the positive changes people perceive as the outcome of the event.
- **Adjustment.** This is generally, though not always, considered as an essential by product of the meaning making process.

Thus, meaning making comprises multiple constructs. It is understood as a carer’s tool of coping with stress related to experiencing the care recipient’s illness. Specifically in psychotic illnesses, it is making sense of the psychotic experience, with internal working through of intense emotions. Psychotic illness of a family member is a vague, unpredictable, and unclear situation where family members give the experience a meaningful form (Stern et al. 1999).
Illness conceptualization, as defined in the present study, includes all the mental representations of the illness. It includes all thoughts shared by the caregiver regarding the care recipient’s condition, which represent the condition for the caregiver. Thus, it is an important part of meaning making, and is similar, but limited to the concept of situation meaning and appraised meaning.

Additionally, the meaning made has important components such as adjustment and a sense of having made sense, which was not in the scope of the illness conceptualization of caregivers explored in the present study.

Emotional experiences and behaviour can be understood as a caregiver-response to their conceptualization of the care recipient’s illness. It includes emotional reactions such as anger, disappointment, sympathy, and empathy; and behavioural reactions such as being critical, hostile, encouraging, over involved, over protective, or displaying neutral behaviour which is not emotionally laden. Help seeking behaviours indicate contact with healers, aimed at alleviating distress of the ill individual (Bannerjee and Roy 1998). Thus, I extended this definition to include any behaviour that the care giver deems necessary to relieve their kin of their distress, such as (visiting healing centres such as hospitals, religious places, visiting family and community elders, etc. Research has often examined emotional reaction in mental illnesses as a construct of expressed emotion. The 5 major areas in this construct are over involvement, criticism, hostility, warmth (Leff & Vaughn 1985)

Expressed Emotion have been shown to associate itself with attribution conceptualization by caregivers in mental illnesses and with burden, especially subjective burden (Scazuufca and Kuipers 1996, 1999, Hooley 1998). The relevance of including expressed emotion in understanding emotional climate at the time of conceptualization becomes high. Thus, the third aspect examined in this study was the association between conceptualizations and varied emotions experienced by the caregiver.

**Situatedness of the Study or the Nature of the Context**

As a researcher, I was interested in studying illness conceptualization as a psychological process. I wanted to understand what kinds of influences were being conceptualised by the caregivers in the illness conceptualization. Situatedness of the illness-recipient and the caregiver were comprehended to achieve a holistic understanding of illness. Anything pertinent mentioned by the caregiver that steered the psychological process of conceptualization of the caregiver was included in the study. I made a conscious effort not to have any pre-conceived notions on the areas of focus, to ensure that the same emerged from the interviews. The purpose of theoretical sampling and
saturation was to exhaust the study of such influences in the sample studied. During the initial interviews, it emerged that the course the illness was running was playing an important role in shaping the illness conceptualizations. Schizophrenia is marked by characteristic phases of premorbid patterns, prodromal phase, and the onset of the overt psychotic symptoms; thereafter schizophrenia runs a waxing and waning course (Kaplan and Saddock 1991). Kaplan and Saddock (1999) described the evolving nature of the illness through these above mentioned phases. Premorbid patterns of symptoms appear before the prodromal phase. These are signs and symptoms that appear before the disease process evidences itself. Care recipients show early signs of aloofness, passivity, and introversion. This is followed by the prodromal phase, lasting for about a year more. The exacerbating and remission course of schizophrenia are marked by relapses. The first relapse is followed by gradual and complete recovery for a long time, however relapsing again within the first five years of diagnosis. Further deterioration in baseline functioning is noted after each relapse, distinguishing schizophrenia from mood disorders. Thereafter, positive symptoms become less prominent while negative symptoms might actually increase. Thus, this ever evolving nature of the illness was making the conceptualization process of the caregiver also extremely dynamic, which then became the focus of my study. Through focussed questioning in subsequent interviews, I tried to chart how the illness experience of the caregiver was providing the context to the ever evolving nature. However, the interviews also revealed that the cultural influences, as well as the socio-economic environment of the caregiver were interacting with the illness experience.

Cultural environment was understood as the cultural context of the caregiver and his family. In cultural psychology, a classic definition is that culture is “a historically transmitted pattern of meanings embodied in symbols” (Geertz 1973: 89, cited in Miller 1997). “The ‘symbolic inheritance’ of a cultural community consists of its received ideas and understandings, both implicit and explicit, about persons, society, nature and divinity…[T]he ‘behavioural inheritance’ of a cultural community consists of its routine or institutionalized family life and social practices” (Shweder et al. 1998: 868). In this perspective, it is also recognized that, while there are many rational bases for cultural meanings and practices, cultural forms are also sometimes beyond reason and empirical evidence. Additionally, these cannot be discerned by mere observation of practices, but can only be understood through being “let in” into the meaning through verbal communication (Shweder 1984). Further, some components of culture might be below the level of conscious awareness where they are not explicitly endorsed by the individual, but they nevertheless direct his thoughts and actions (Hatch 1985). This understanding of culturally shared values and meaning was particularly suited to the present study. It was found useful in explaining the culturally shared notions, templates, schemas, and validations used by the caregiver in interpreting the care recipients’ behaviour.
The Research Site

The choice of the research site was governed by both purpose and convenience. A charitable private hospital in the suburbs of Mumbai was chosen. The hospital caters to a population belonging to a wide range of socio economic groups, although the extremely elite, highly educated, and very high socio economic group are not a part of the hospital’s clientele. However, this site offered most variation in the socio economic background of the participants. It was also relatively more convenient for me to access participants in this hospital compared to other hospitals since many families visiting the hospital were receiving free consultation and were willing to help the department for research purposes. This is very crucial to any psychological research, especially that related to mental health. However, I did have to deal with the issue of stigma with the families of mentally ill. The family wanted to avoid discussion with non-helpers about the affected relative because of the perceived shame and feelings of emotional pain associated with the condition. As I was not directly involved in the healing, I had to put in substantial efforts in building rapport and a sense of trust with the respondents to help them feel comfortable to share their experiences with me.

Participants

Caregivers of individuals living with schizophrenia were the participants of the study. Caregivers are individuals who are currently primarily responsible for the caregiving of the care recipient, generally a kin of the individual, devoting most of his/her time to the task of caregiving, receiving no economic returns. Only those who provided informed consent were interviewed. Since the family is the main unit of care giving, siblings, parents, spouse, and children were the main set of caregivers interviewed.

Selection Criteria

Caregivers who were primarily responsible for the care recipient’s care giving at the time of data collection were selected. However, as interviews progressed, it was realised that owing to the co-morbidity of other psychiatric illnesses in the care recipient, e.g. substance abuse, the affective symptoms were drawing caregivers’ attention to those conditions also, thereby increasing the scope of the study to a great extent. It was difficult for the caregivers to conceptualize schizophrenia as they were rather focussed on other problematic issues arising out of the psychiatric conditions such as the legal issues with substance abuse, abuse from care recipient due to alcoholism, and extra spending related to elevated moods. It was also confounding the primary
objective of the study, which was to understand the caregivers’ conceptualization of schizophrenia. Therefore, I restricted the sample to caregivers of care recipients with schizophrenia with no co-morbid physical or psychiatric conditions.

With a clinical practice background, I was aware that some of the caregivers, who were themselves suffering from psychotic conditions, would find it difficult to clearly organize their thoughts and express them. Therefore, caregivers with (diagnosed) psychological conditions were also excluded from the study, as their emotional reactions were inextricably linked to their conceptualization of their own illness and the care recipient’s illness.

Sample As is true for any study employing the grounded theory approach, the sample characteristics were not predetermined in the present study. Indeed, divergence in the characteristics of the participants was ensured to tap the various perspectives on the study focus. While theoretical sampling, the hallmark of the grounded theory approach, has been explained in detail in the section on research procedures, along with how divergence in the characteristics of the sample was achieved, the details of the effective sample have been presented in Table 2.1. The sample consisted of caregiver of the care recipient diagnosed with schizophrenia. The sample belonged to lower and lower middle income group and had a homogenous economic background. They were theoretically sampled for education and thus education level varied from being illiterate to post graduate. All the caregivers were first and second generation rural migrants. Majority caregivers were parents followed by spouses. There were very few sibling and children. Mothers were the largest majority among caregiver followed by father. Women are expected to take up the role of caregiving, which explains their predominance in the sample. Amongst men caregiver majority were spouses, followed by fathers and a brother. Most of the caregivers were married. Care recipients age range was 16 years to 55 years reflective of the long course the illness runs.. Again education levels of care recipients varied from elementary educated to graduate. To capture caregivers at different points of caregiving care recipients at different stages of illness, manifestations, and healing histories were selected for the purpose of theoretical sapling.

The following page numbered 76 shows table number 2.1 depicting detailed sample characteristics.
<table>
<thead>
<tr>
<th>Pseudonym of care recipient</th>
<th>Age of care recipient</th>
<th>Marital status</th>
<th>Illness experience</th>
<th>Nature of onset</th>
<th>History of Intervention</th>
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**Notes:**
- Pseudonym of care recipient refers to the name used to identify the care recipient.
- Age of care recipient indicates the age of the care recipient.
- Marital status indicates the marital status of the care recipient.
- Illness experience indicates the relapsed or first episode status.
- Nature of onset indicates whether the illness is physical or behavioural.
- History of Intervention indicates the type of intervention for the care recipient.
- Age of caregiver indicates the age of the caregiver.
- Relationship indicates the relationship of the caregiver to the care recipient.
- Education caregiver indicates the education level of the caregiver.
- Migration history indicates whether the care recipient is an urban dweller or migrant.
- Socio economic status indicates the socio-economic status of the caregiver or care recipient.
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Table 2.1: depicting detailed sample characteristics.
**Research Method**

As explained before, qualitative methodology was used to pursue the objectives of the study. Here the main aim was to understand and discover the conceptualizations of caregivers rather than to predict or control any aspect of the phenomenon. Qualitative research methods have been found to be most effective for the above objective (Knafl and Deatrick 1987). Though some quantitative tools such as the Illness Perception Questionnaire (IPQ) are available, these tools include a fixed ranged of predetermined causal explanations from which patients can identify the one closest to their own views. This method assumes that the ranges of beliefs that are of interest are largely known, and that the constructs presented in the questions are familiar to people from different cultural and linguistic groups. However, my assumption was in direct contrast with these widely used tools. Based on a constructivist approach, I assumed that there is no fixed and uniform definition of mental illness. Thus, a qualitative approach was best suited for examining this form of subjective conceptualizations.

The grounded theory approach informed the research methodology. Grounded theory consists of systematic inductive guidelines for gathering, synthesizing, analysing, and conceptualizing qualitative data to construct theories (Charmaz 2001). The grounded theory method is suitable for studying individual processes, interpersonal relationships, and reciprocal effects between individual and larger social processes (Charmaz 2005). Strauss and Corbin (1994) define grounded theory as a general methodology for developing a theory that is grounded in data that is systematically gathered and analysed. *Constant Comparative Analysis* (Strauss and Corbin 1994, Charmaz 2000) is the characteristic feature of grounded theory. This means that there is a constant back and forth movement between data collection and data analysis. Analytical insights from the data give the further direction to future data collection. This process of interplay between analysis and data collection refines the theoretical insights.

The ‘interpretive work’ emphasis of qualitative research is maintained in the grounded theory approach. Here too, the ‘voices of people’ are used to reflect their perspectives (Strauss and Corbin 1994). However, what distinguishes the grounded theory approach from the other qualitative approaches is its ultimate goal of theory building. Strauss and Corbin defined theory as “plausible relationships proposed among concepts and sets of concepts” (Strauss and Corbin 1994: 278). A grounded theory is conceptually dense, that is, with many conceptual relationships; it is embedded in a thick context of descriptive and conceptual writing and it describes a process – “of reciprocal changes in patterns of action/interaction and in relationship with changes of conditions either internal or external to the process itself” (Strauss and Corbin 1994:278). In addition, grounded theories are embedded in the data that gave rise to them (fit) and are also very fluid (modifiable).
because of their premise of multiple realities and actors, and openness and acceptance of new empirical data.

**Research Procedure**

This section describes how the objectives were achieved through use of the grounded theory methodology. This includes going to the field, gaining access to participants, setting up relationships with the participants, collecting the data (interviewing), and analysing the data using the principles laid down in the grounded theory methodology.

**Accessing Participants**

Keeping in mind principles of reflexivity (Holliday 2007), it was felt necessary to discuss how my presuppositions played a role in shaping the methodology. Thus, while the basic procedures of the study have been discussed, this section also discusses the reflexivity engaged in.

The research site was chosen was based on practical considerations. Since I was pursuing Ph.D at the Tata Institute of Social Sciences, Mumbai, the same was the city of choice for data collection. Consent had to be procured from the head of the academic unit of the hospital. Once the approval had been received, further approval was sought from the head of the psychiatric department. Once all approvals had been received, the data collection started. The first interview was conducted in March 2013, and the data collection continued up to January 2014. In keeping with the constant comparative analysis technique used in the grounded theory approach, the data collection and data analysis were conducted simultaneously.

Locating participants for the interview was easy. The department of psychiatry had a heavy flow of patients with a regular number of visits by caregivers of care recipients with schizophrenia. However, owing to the issue of unfamiliarity with me explained before, securing consent for the interviews was difficult. Additionally, several caregivers declined the request for interviews because they found the time required for the interview was too long to sit through. Therefore, often interviews were broken into 2 or more sessions. On some occasions, the interviewee did not visit the department at the fixed appointment or came on another day and met the mental health professional and left. Many a times interviews were left incomplete as the interviewee was either in a hurry to go back home or their turn to meet the health professional had come. There was no particular motivation for the participant to participate in the interview except for an altruistic motivation. Further, the hospital had a policy that no kind of reinforcement (cash or kind) could be provided to individuals seeking treatment. Majority of the participants who were willing to spend
some substantial amount of time were those who were waiting to meet the health care professionals or whose care recipient was admitted in the hospital. Working with these restrictions made data collection a slow process that required patience.

The Interview Process

The interviewees and their respective care recipient were explained the research purpose and the procedures of the study. They were informed about the protocols followed for confidentiality. Only verbal consent was taken as written consent was making them suspicious of my motives. Majority of the interviewees enquired about the benefit of such a study. It was explained to them that such a study would help increase knowledge about a caregiver’s perspective and inform professionals about better ways of helping them. Even though they were informed adequately about confidentiality, most of them, at the beginning of the interview would enquire about how their identity would be kept a secret. Additionally, one care recipient with paranoid schizophrenia forced to stop the interview as he thought I was representing a newspaper and was going to publish his story in a leading daily. Thus, the interviewing also involved provision of a lot of reassurance to the participants about confidentiality and anonymity of the participants.

As the participants and I were well versed in Hindi, all interviews were conducted in Hindi. An interview guide (described in the next section) was used to aid the interview. Since, I was not the healing professional, the caregivers were not interested in talking to me at the outset. Indian help seekers are compliant with healers; therefore, the treating resident psychiatrist introduced me and requested the caregivers to spend some time with me. I also sat inside one of the consulting rooms to gain easy access to the caregivers. The department head allowed me to sit through the interviews of care recipients and caregivers conducted by the residents, such that I could assess whether the caregiver met my selection criteria. Despite my best efforts, I initially felt like an outsider in the department, and my discomfort was influencing my interviews. However, with passing time, I grew more comfortable, felt that I was a part of the team, and helped them out in assessments when required. This helped me become more relaxed and confident in the way I approached the caregivers and interviewed them.

All interviews were conducted in the hospital premises, in one or two sessions. A digital recorder was used and the reason for using it was explained to the participants. None of the caregivers were uncomfortable with the use of the recorder.

In the interviews, I ensured that I avoided technical jargon while speaking with the caregivers. I was aware that majority of the individuals visiting this hospital belonged to the lower socio
economic status and had lower levels of education, with lower awareness of such jargon. I kept my language simple to help them feel comfortable, both in understanding my questions and expressing their thoughts freely. Conversations had to be kept open so that the respondents came forth with the nuances of their thoughts, emotions, and experiences. I kept an approachable demeanour. I was dressed in work clothes and chose not to wear the white apron so that interviewees did not perceive me as representing the hospital staff. I did not want them to feel any inhibition in sharing emotions of any kind e.g. dissatisfaction towards the current management techniques. I also avoided the conventional seating arrangement of chairs on opposite sides of the table. I seated myself next to the caregiver to make him/her feel comfortable and at ease to speak his/her mind. I wanted to convey the message that I was there to just hear his/her thoughts and not treat anyone. Yet, I did realize that sometimes I was perceived as one among the medical community and was often told ‘you experts know everything, what can we explain to you’. However I reassured them that their thoughts mattered to me and that they can express freely.

During the interviews, several times, I was asked to share my opinion on the diagnosis and the intervention plan of the hospital. I refrained from commenting on the diagnosis as I was not present at the time of discussion of presenting complaints which are essential for diagnosis. However, I did suggest a few methods that could alleviate distress for the family, which did not contradict in any way the medical management going on. This further helped me develop a relationship of trust and sense of mutual benefit in the minds of the respondents, which aided their sharing.

The interviews were an emotionally overwhelming experience. Although I have worked with caregivers throughout my professional life and have been assisting them in their trials and tribulations, it never stops to impact me to see the suffering involved in families with mental illness. However, it also amazed me how, despite the multitude struggles such as poverty, legal battles, and loneliness, caregivers were trying their best to wade through the crisis.

**Tools Used**

*Socio Demographic Clinical Data Sheet.* The details elicited in the socio demographic data sheet included demographic information about the care recipient, such as name, age, sex, education, employment, socio economic status, religion etc., as well as information related to clinical variables such as diagnosis, age of onset, number of episodes, comorbid conditions among others.
The caregiver information sheet had similar sections, except for information related to any chronic physiological or psychological conditions (Annexure I).

**In-depth Interview Guide.** An interview guide was developed based on the purpose of the study and the lines of inquiry (see Annexure II). Though the interviews were conducted according to the flow of the conversation with the interviewees, the interview guide was used to ensure that all aspects of the research focus were covered during the interviews. Thus, to begin with, the interview guide included open ended questions regarding the caregivers’ conceptualizations and the events and conditions from their environment facilitating the same. The interview questions had phrases such as ‘tell me your thoughts about this’, ‘what do you know about this?’, ‘what have you understood?’ etc. As the interview progressed and the impact of the evolving nature of the illness became the focus of the illness, questions focussing on how it was influencing the illness conceptualizations were included in the interview guide, such as ‘what were you thinking at that time?’, ‘so after this happened, how did you view his/her condition?’, ‘how has it changed you understanding?’ etc. As the study also aimed to explore the emotions associated with the caregivers’ illness conceptualizations, since the beginning, the interview questions also focussed on the emotionally laden thoughts and the association between emotional states and conceptualizations. These questions included ‘How were you feeling at that time?’, ‘How did that make you feel?’ and ‘Can you describe a day in your life at that point?’

**Sampling**

**Sampling for open coding.** Aim of open coding is to discover, name, and categorize phenomena according to their properties and dimensions. Thus, data gathering is aimed at keeping the data collection process open to all possibilities (Strauss and Corbin 1990). Following these guidelines, I interviewed caregivers who came to the department, met the selection criteria of my study, and provided consent to participate in the study.

Theoretical sampling is the recommended sampling technique for grounded theory (Strauss and Corbin 1990). Charmaz (2003) recommends it to be used a little late in the sampling process, when issues and concepts already start emerging, as early theoretical sampling may result in premature closure. It is defined as sampling that is conducted on the basis of concepts with proven theoretical relevance to the evolving theory. Charmaz (2006) recommends that one should conduct theoretical sampling by sampling to develop the properties of the categories until no new properties emerge.
Theoretical sampling has various aspects. Engaging in theoretical sampling prompts one to predict where and how one can find the needed data to fill gaps in the data and to saturate categories. Obviously, this is facilitated by simultaneous data collection and analysis. Another aspect is that theoretical sampling entails simultaneous engagement of inductive and deductive reasoning. It involves abductive reasoning whereby one compares cases, then formulates tentative hypotheses from the data, and subsequently goes back to the field to check it. Theoretical sampling is emergent. It is followed by the construction of tentative categories. The main aim of theoretical sampling is to increase variations in the category and saturate them. Dimensional range or variation in a category is achieved by gathering data that demonstrates variations in a category and sub category. Therefore, one seeks data that illuminates the variation and relationships between categories and sub categories. This enables the axial coding to take place.

Theoretical sampling was employed in the present study to understand the themes of illness conceptualization, the important influences of the environment on the same, and the emotional experiences and behavioural reactions of caregivers with reference to illness conceptualizations. It was also used to pursue the understanding of the milestones of the illness course, as that was found to be an important influence on the illness conceptualization of caregiver. Through theoretical sampling, I elaborated the meaning of the categories. To facilitate deeper understanding of the research process in the grounded theory approach, the subsequent paragraphs illustrate how the emergent theory was pursued through theoretical sampling.

While interviewing caregivers, the label ‘pagal’ emerged as a prominent category. Then the line of enquiry was modified to include elaborations on the meaning of the label ‘pagal’. More properties of this sub category emerged such as equating this condition as loss of control, being a prototype of the image of insanity depicted in the media. Theoretical sampling was used to study variations in categories. When I wanted to know how the caregivers were defining their care recipient’s illness, it was almost clear that at some point during the course of the care recipient’s illness, they had entertained the hypothesis of it being an issue of possession or black magic. Once this theme emerged, the next interviews focussed more on their belief about possession and black magic. These focussed interviews revealed more insights and variations in the same were mapped. The data revealed variations in the participants’ degree of faith in the belief in these alternative explanations. A continuum of conviction was found. While some saw it merely as a hypothesis, others believed it to be the only possible explanation of the care recipient’s condition.

Theoretical sampling also guided the examination of variations in the process of conceptualization. While caregiving, caregivers showed variation in how they defined mental illness. Theoretical sampling illuminated how the caregivers’ definition of the care recipients’ condition exhibited
inter and intra individual differences. Since I understood that at the beginning itself, I collected information on this in two ways. Focussed questioning was used regarding the past conceptualization of every caregiver. I also started to seek out individuals who were at different points of caregiving during the data collection period. Although a longitudinal study would have been better suited for the purpose, time and resource constraints did not permit the same. However, theoretical sampling, which involved focussed questioning on past conceptualizations and sampling of caregivers at different stages in the course of care recipient’s illness helped in the same.

It is important to note that, in the present study, the theoretical sampling was not pursued according to education of care recipient, type of residence, or socio economic status, as that would increase the scope of the study immensely, and saturating each category in a single study would be difficult. Given the limitation of time and resources, it was thought best to limit the theoretical sampling to saturating the themes related to the emerging theory.

Data Analysis

Transparency in the research procedure, especially in data analysis, is the hallmark of qualitative research. I organized and managed the data manually, as I was more comfortable in doing that. Thus, the interviews were transcribed and then translated from Hindi to English. The analysis started with open coding of the data collected from the first case, where I started line by line coding. Open coding is the analytic process through which concepts are identified and their properties and dimensions are discovered from the data (Strauss and Corbin 1998). The following are the goals of open coding (Strauss and Corbin 1998):

- **Conceptualization**: Data is broken down into discrete incidents, ideas, events, and acts, and are then given a name that represents or stands for these.

- **Digging deeper into analysis**: The purpose to dig deeper is to discern the range of potential meanings in respondents’ phases and to develop the properties of the concepts.

- **Discovering categories**: Categories are concepts that can stand as a phenomenon. Categories are driven by the research context and, in the case of constructivist grounded theory, the analyst’s interpretations. The process of category development also requires focus on development of properties and dimensions of the categories. Properties are characteristics of the attribute, while dimensions are the location of the property on a continuum.
Line by line coding is a technique for conducting open coding. It is a close examination of data where one focuses on every phrase and word in the interview transcripts (Strauss and Corbin 1998). Subsequently, I labelled these codes (Charmaz 2006). The initial codes were provisional, verbatim, and comparative. Gerunds were used, which made initial codes more active rather than descriptive. Data was constantly compared within the same interview as well as between interviews. Similarities and dissimilarities between ideas were mapped.

Following is an interview with Needhi’s mother, whose daughter had received a diagnosis of schizophrenia only one week prior to the time of interview. The following is an excerpt from her interview, with my codes expressed in italics:

```
C: This is what saddens me the most.
    reason that most effecting emotionally.
    We had dreamt really big for her.
    
    Crashing of expectation.
    
    Assuming fullest potential will not be realised
    
    Feeling regretful.
    
    I: What dreams?

C: Madam she had very good qualities (breaks down).
    Loss of the star child.
    She was very good in studies. She never troubled us.
    Identifying qualities of perfect CR.
    Till 12\textsuperscript{th} I never had a teacher make a single complain about her.
    CR as a well behaved student.
    Forget teachers, even students never said anything bad about her.
    Having a good reputation.
    I got so many praises on her behalf.
    Bringing appreciation to CG.
    They used to say what a quiet girl she was.
    Having a good impression on others.
    Even as a child she never troubled me.
    Having an easy parenting experience with the CR.
    Amongst the 5 kids, she was the best.
    Emerging the best on comparison with others.
    I have 2 kids and my sister in law has 3 kids.
    Comparison amongst cousins.
    She was better than everybody in everything.
    Outperforming cousins.
```

From this coding, I got more interested in what the caregivers felt the illness had done to their care recipient. I used more focussed questions to understand what they meant when they said he/she was not the person they used to be, and I finally raised this concern of the caregiver to the category of the ‘loss of the perfect person’. The constant comparative method was used to note similarities and dissimilarities between and within each interview. Additionally, the comparison was not only
conducted data to data, but codes and data were also compared to check for representativeness and to achieve refinement.

As interviews progressed, the phase of focussed coding was entered. These codes are more conceptual and more significant to the objectives of the study (Charmaz 2008). These more significant and frequently appearing codes were used to synthesize and explain large amounts of data. The following is an excerpt from the interview of Sunita’s mother, whose daughter had been living with schizophrenia for the last 14 years. This excerpt was coded for other themes, as well as for the theme ‘loss of the star child’. Again, the coding has been expressed in italics.

Oh my God I feel like crying I go to the toilet and cry.
Overwhelming feelings of sadness.
Concealing outbursts.
My bright girl...she was earning. She was my only girl. I don’t want her to earn only ...her brain should work properly, like before. 4-5 years she is alright and then again her brain starts getting spoilt. I went mad. Why this happened to my daughter. They used to say she is the best girl. She never sees anyone with an evil eye.
Loss of the perfect person/does not make sense/Hopelessness.

In the next phase, a higher level abstraction was aimed at. After studying the similarities and differences in the data, similar codes were grouped together under more conceptual codes. This process is identified as axial coding. Axial coding the process of relating categories to their sub categories, termed ‘axial’ because coding occurs around the axis of a category, linking categories at the level of properties and dimensions (Strauss and Corbin 1998). ‘Paradigm’ is a tool available for axial coding. It is described as an organizational scheme that informs data gathering for the purpose of integrating structures and processes. Paradigm has various components such as phenomenon and conditions. Phenomenon entails repeated patterns of happenings, events, or actions/interactions that represent what people do or say in response to problems and situations they find themselves in (Strauss and Corbin 1998). Conditions are set of events/happenings that explain why individuals react the way they do. An example of axial coding in the present study is that all the codes depicting the way the caregiver called the condition of the care recipient e.g. ‘pagalpan’, ‘chakram’, ‘schizophrenia’, etc. were grouped under the conceptual code of ‘labelling the condition’.

When newer aspects were revealed, old data was re-examined to check for coding variations in properties. To arrive at a well grounded theory, the entire coding process must culminate in to a selective coding phase. Selective coding refers to “the process of selecting the central or core category, systematically relating it to other categories, validating those relationships, and filling in categories that need further refinement and development” (Strauss and Corbin 1990:116). The authors describe it as the process of integration and refinement of the data. Here, higher level
categories were related to each other and the contexts operating. Following selective coding procedures, milestones in the course of the care recipients’ condition was found to be related to the caregivers’ illness conceptualizations. Theoretical saturation was aimed at exhausting the properties of the themes of illness conceptualization and the environmental players. Theoretical saturation was also followed for chronicling all the milestones in the course of care recipients’ illness and its relationship to illness conceptualizations of the caregivers.

Thus, gradually, the emergent theory was clarified. Findings related to the three core objectives of the present study have been reported in the following three chapters, after which, the emergent theory has been reiterated and discussed in light of the existing literature.