# SCHIZOPHRENIA: A WAY OF BEING-IN-THE-WORLD

A thesis presented in fulfilment of the requirements
for the degree
of Doctor of Philosophy
in Nursing
at Massey University

Jo Ann Walton

October 1995

# ABSTRACT

This phenomenological study describes what it is like to live with a schizophrenic illness and relates the understanding gained from this descripton to implications for nursing practice. The participants in the study were ten adults who have been diagnosed with schizophrenia, who take regular medication and who are living independent lives in the community. Over a period of sixteen months they were interviewed about the effects of the illness on their everyday lives. During this time they explained the challenges and difficulties which have faced them, both during and long after the resolution of acute illness. As they describe it, schizophrenia is a part of who they are.

The narrative contained in this thesis presents the participants' stories in aggregated form, setting their experiences alongside ideas from the early work of Martin Heidegger, whose phenomenological writing informed the analysis and interpretation of the data. As the participants explain, schizophrenia has touched every aspect of their lives. Living with schizophrenia is shown to affect their whole Being-in-the-world. It incorporates ***Being-with-others, living carefully*** and ***taking a stand on life***. While hoping for a cure, their reality is of living with a chronic illness which has major effects on their lives. At the same time the participants are shown to define themselves not in terms of their illness and treatment, but in respect of their hopes and dreams and the stance each is taking on his or her own life. In this way their existential predicament is highlighted in the study. Participants are on the one hand very much like all other people, while on the other hand they have to contend with very different concerns than do most others.

In itself the description of the experience of schizophrenia contained in the thesis is useful for its potential to increase understanding of the illness by nurses and other health professionals. Further than this, however, the study is shown to have implications in terms of nursing practice and the provision of health care. With regard to the seriously mentally ill the data bring into question some of the theoretical positions which have held sway in nursing for many years. The research demonstrates that it is practicable to attend to the subjective experiences of people who suffer from schizophrenia and to understand their needs and desires from the position of fellow human being, without the need for a guiding theory from which to interpret what they are saying or what their words "really mean." It is argued that relationships between nurses and clients which are based on understanding and trust rather than distance hold promise in the care of those with schizophrenia. Heidegger's concept of *solicitude* as care for others is addressed in this regard, and is shown to be most appropriate as a basis for nursing care in the mental health arena.

# ACKNOWLEDGEMENTS

This thesis could never have been written without the help, guidance and support of many people. In acknowledging those who have enabled me to complete this research I wish first to express my sincere thanks to the study participants, who shared their personal stories and gave so generously of their time and their hospitality. I am deeply grateful to them for making the study possible, and trust that their gift will go some way toward encouraging positive changes in the health care that those with schizophrenia receive.

My supervisors, Professors Norma Chick, Irena Madjar and Linda Chafetz have travelled the past four years with me, offering a perfect mixture of advice, challenge and gentle encouragement, each in their own way. I owe them each particular thanks for their wisdom, time, thoughtfulness and support and for the learning they have fostered in me throughout the process of the research.

I have been supported by too many friends, family members and colleagues to name everyone. I would like to express my thanks to my colleagues at Massey University, in particular Jan Rodgers for her wise words of advice and understanding regarding the loneliness of the PhD process, Marion Pybus who was so often there with encouraging words and a listening ear at strange hours, Denise Dignam who stood in for me when I was busy elsewhere, and Dorothy Clark whose tact, practical skills and sense of humour have helped me surmount both technical hurdles and personal setbacks as and when they arose.

My friends and family have been a constant source of both practical and moral support. They have ensured a constant supply of love, patience, understanding and good humour and tolerated my lengthy absences, absent mindedness and preoccupation. I wish particularly to thank Charlie, Lynn, Ron and my three children, Piers, Erika and Hugh, each of whom has played a special role in my completing this work. Thank you all for believing in me, for your commitment to the importance of this study and for your central place in giving my life meaning.

Finally I wish to acknowledge the financial support I have received from Schizophrenia Fellowship, the Nursing Education and Research Foundation and the Massey University Research Fund, and the time made available through the Research Award for Academic Women.

# TABLE OF CONTENTS

CHAPTER THREE:

CHAPTER FOUR:

CHAPTER NINE:

# KEY TO TRANSCRIPTS

The following information explains the meaning of abbreviations and conventions used in the presentation of research findings, particularly where excerpts from participant interviews are included in Chapters Four to Seven.

| | |
|---|---|
| Names: | All names used to refer to study participants, their family or friends, or to health professionals, are pseudonyms. Excerpts from participants' interviews are identified by pseudonym, interview number and page reference to the transcription, eg. (Lucy 2, p. 5). |
| *Italics*: | Where sections of interview data are reported, the participants' words are given in italics. |
| (plain type) | in interview excerpts the researcher's words are given in plain type inside parentheses. |
| (parentheses) | included in sections of participant speech indicate such things as the actions of a participant, eg. (laughs), or the name of a place such as a hospital which has been removed for reasons of confidentiality. |
| [square brackets] | are used when a clarifying or explanatory comment has been added by the researcher. |
| .... | indicates a pause contained in the original material |
| ..//.. | material edited out |

# INTRODUCTION

There are few illnesses in today's world as baffling as schizophrenia. It is an enigma not only for those whose thoughts, perceptions, emotions and behaviour it so seriously disturbs, at least in its acute phases, but also for the generations of researchers, theoreticians and clinicians who have studied it since it was recognised as a distinct illness 100 years ago. As one of the most serious of mental disorders, schizophrenia has been both extensively researched and widely feared. It remains an illness about which comparatively little is known, but undoubtedly the effects upon those who live with it are profound.

The Latin saying "Whom God wishes to destroy He first makes mad"[1] is not far removed from the suggestion that schizophrenia is "a sentence as well as a diagnosis" (Hall, Andrews & Goldstein, 1985, cited in Torrey, 1988, p. 1). The sense of tragedy conveyed in both these sayings is understandable. Schizophrenia is an illness whose cause (or causes) is unknown, for which there is no known prevention and no cure. Estimates of recovery rates vary considerably, but it is widely held to be a long-term illness in the majority of cases. It has even been suggested that schizophrenia affects people so cruelly that it "leads to a twilight existence, a twentieth-century underground man" (Torrey, 1988, p. xv).

In fact little is known about what it is like to live with the illness, since to date the scientific community has paid only sporadic attention to the experience of schizophrenic patients. We have limited knowledge about the common experiences of people with the illness, and about the effects the illness has on their lives. Nor has much consideration been given to patients' evaluation of the health services provided for them or suggestions they might have for its improvement (Rogers, Pilgrim & Lacey, 1993). The research reported here addresses that gap. This thesis is about the subjective experience of schizophrenia and the effects of the illness on those who suffer from it.

There are several reasons why research which examines the experience of people with schizophrenia has seldom been undertaken. It may be because communication difficulties are so often a part of the illness that both researchers

---

[1] Quos Deus vult perdere, prius dementat

and those who suffer from the illness have come to believe that the experience is not available to capture by words. This belief is expressed in an autobiographical account of the illness in which the author explains his difficulty in making himself heard, even by those whose intention is to listen:

> I find it difficult to communicate my experiences even to doctors. When I tell them that I can't walk very far because the arteries in my legs are furred up they cotton on immediately. When I tell them about my deafness there is less understanding and possibly comments such as "It must be difficult for you." When I tell them that I suffer from schizophrenia I often get blank looks and sometimes a very wary one. I have often felt that the mad cannot explain and the sane cannot comprehend.
>
> (As in Dreams, 1975, p. 47)

It is not only those with the illness who feel that communication is difficult, if not impossible. For decades European psychiatrists have recognised the "praecox feeling," a strange sense of differentness, an alien quality, in people who have a schizophrenic illness (Sass, 1992a). Sass argues that this sense of aloofness is felt at the human level.

> In the presence of normal people, as well as with patients of nearly every other psychiatric diagnosis, one feels an immediate sense of a shared humanity, whereas the schizophrenic seems to inhabit an entirely different universe; he is someone from whom one feels separated by 'a gulf which defies description'.
>
> (p. 14)[2]

In embarking on the research described in this thesis I set out to discover more about this "different universe" and to describe the world of the schizophrenia sufferer from his or her perspective.

If descriptions such as those above, which highlight the inaccessibility of the schizophrenic experience to others, were entirely accepted by nurses and other health workers, then little would be done to help people come to terms with the illness and to adjust to their lives in the face of such a diagnosis. In fact

---

[2] The brief quote made by Sass is from Karl Jaspers (1913/1963).

psychotic states (in which sufferers are most difficult to understand) are usually short lived, assistance is available, and the vast majority of people who have been diagnosed as having a schizophrenic illness now live in the community. The gulf, if it exists, is not an unbridgeable one. Indeed, as this thesis will show, neither is it as wide as it has been believed to be.

In recent years prevailing humanitarian and economic rationales have resulted in a virtually universal move toward the closure of institutions for the mentally ill and the reintegration of those with mental illness into community settings. Many people who are diagnosed with a major mental illness may now never be hospitalised at all, or may receive hospital treatment for only a very brief time. As a consequence people with mental illness are becoming more visible in the community and some groups are becoming more effective in advocating on their own behalf.

It is becoming apparent that those who suffer a mental illness and remain in the community face different challenges to those which existed in institutions. Although community care is not new in New Zealand, in the wake of the present upsurge it has received renewed media attention. Media reports which emphasise the bizarre and dramatise the poor conditions in which some people with mental disorders are found to be living, both reflect, and feed, the community's deep seated fears of violence. Mental health consumers and family support groups are faced with the challenge of overturning prejudice in the community, and increasing understanding of mental illness amongst the general public. Alongside the need to manage their illness, people who suffer from schizophrenia continue to struggle with prejudice and stigma in the communities in which they live.

If effective community care is to be offered to those with schizophrenia and other mental illnesses it is important that their experience is understood. Those who aim to help, especially nurses, cannot afford to conclude that such understanding is not possible. Researchers from other disciplines are also beginning to recognise that increased understanding of people's experience of illness is needed in the mental health field. The deficit in the literature is pointed out by Strauss and Estroff (1989, p. 177) who write:

> There is something seriously missing in a field of mental illness that does not attend closely and broadly to patients' subjective experiences and sense of self. And, yet, much of the contemporary scene in disciplines that focus on mental illness reflects this neglect. Driven by various theoretical models or the quest for being scientific only in a narrow sense, clinicians neglect many aspects of patients reports, their implications for understanding illness and healing processes, and the need to develop improved methods for studying subjective experience and sense of self.

Understanding the experience of illness, defined by Kleinman (1988, p. 3) as "the innately human experience of symptoms and suffering" rather than disease (which is equated with pathology) is of particular importance for nursing. Morse and Johnson (1991) assert that understanding illness will lead to more effective health care. Indeed in recent years nurse researchers, understanding the pervasive manner in which long-term illness affects people's lives, are becoming increasingly interested in the experience of living with persistent illness (Packard, Haberman, Woods & Yates, 1991). As yet, however, as the latter authors point out, the knowledge base stemming from such interest is not sufficiently developed to guide nursing practice. This thesis is based on a phenomenological study which set out to record the subjective experiences of a small sample of adult sufferers of schizophrenia, living in the community, and then through reflection on the data to relate the findings to the world of nursing practice. Aldiss (1989, p. viii) quotes Carl Jung as saying "All we see of the mentally ill regarding them from the outside, is their tragic destruction, rarely the life of that side of the psyche which is turned away from us." This study was designed to try to see something of the side which is turned away.

## Background to the Study

My personal interest in the topic of this research developed over a period of many years. In the course of clinical practice in acute psychiatric settings and a day care centre, personal contact through friends, and a spell as residential supervisor of a hospital "half-way house" I have met many sufferers of schizophrenic illness at various stages of health or distress. It has been my experience that those in the caring professions may have considerable knowledge of the ill person yet little comprehension of the context of that person's whole life apart from their illness, or how they function when they are well. We often know little about people's potential for taking charge of their own lives, about their social relationships or their future expectations. We do not always know how well *well* is for particular patients, how they manage their affairs, and how their everyday lives are conducted in the absence of acute illness. Seeing people when they are unwell sometimes has the effect that the whole person is seen as existing in this state, even when we know this can not be the case. How do we know if we are setting our sights too low, or too high, in efforts to "rehabilitate"? Do we expect too much or too little in terms of independent living?

Such concerns are made more pressing by an appreciation that there is an increasing need for nurses to work within interdisciplinary health care teams, where multiple, and sometimes conflicting, theoretical understandings of mental illnesses may be held even if not articulated. These understandings influence the work of team members, both individually and as a group, and impact on the expectations that team members have for clients.

Shortly before I commenced the study, two people whom I had known as patients committed suicide. The circumstances of each of these unrelated tragic deaths was such that each had come to hospital asking for help and had been turned away. Both incidents made me question the place of medical and nursing help in the lives of these people, and reinforced my idea that there was more we should know about how a severe illness such as schizophrenia affects the lives of those who experience it. At this point I hypothesised that the hospital played a central role in the lives of some people so affected (they visited frequently and we, as nurses, knew them as "regular customers"). However, attendance at the funeral of one of the patients put paid to my notion of carers holding a central place in her life. I had imagined a quiet funeral for this young woman, but in fact there were so many friends and supporters present that there was insufficient seating room at the church. Again I realised how little I knew about the daily life of people with schizophrenia. My concern to find out more about the effect of the illness of people's lives stemmed not just from curiosity, but from the belief that understanding is crucial for nursing: in the development of therapeutic relationships, in setting realistic treatment plans and in evaluating need.

## Purpose of the study

The purpose of this study was to explore the lived experience of schizophrenia. To this end a Heideggerian hermeneutic approach was taken, the fundamental question being "What is it like to be-in-the-world in this way?"

Understanding is a major precondition on which the therapeutic relationships sought by nurses, and other health professionals, are founded. The better health professionals are able to understand the experience of any of the clients with whom they come into contact, the better able they are to provide effective support, and useful intervention, and to assist people in the fullest living of their lives.

Liaschenko (1989, p. 156) suggests that to understand illness one must understand the meaning of the experience in the context of the patient's life. In similar vein, Barker (1989, p. 132) refers to the emphasis of many nurse authors that "nursing is primarily about helping people in their complex personal relationship with illness." Nurses are in contact with schizophrenic clients in many areas of their work. They interact with both the acutely psychotic and the well functioning, minimally disabled client, in institutional and community settings. To date there is a gap in the knowledge that underlies practice in these areas. It is believed that the knowledge resulting from this study has ramifications for practice wherever nurses work with this client group.

There is a recent move by the media and amongst health administrators and rehabilitation workers to refer to the "psychiatrically disabled," rather than the "chronically mentally ill." In part the renaming serves to decrease the very real stigma experienced by those who suffer from some kind of mental illness, but it also serves to refocus interventions toward assistance in everyday living, rather than care for someone who is ill. The "well" functioning of these people is thus emphasised over the illness. Nursing's place in this view is to consider the "enhancement, fulfilment, and enrichment of human life - the meaning one find's in one's existence" (Watson, 1989, p. 125). In the literature little evidence was found relating to the kind of research which would indicate nursing's preparedness for this change in emphasis. This is another gap in clinical knowledge which the study was designed to address.

In conducting the present study my concern has been to extend understanding of the impact of schizophrenia on the whole of people's lives. The research findings are presented with the aim of deepening the understanding of nurses and others of the significant effects which schizophrenia has on the physical, emotional, relational and spiritual dimensions of the lives of those who have the illness. It is my hope that nurses and others who read the study report will find themselves reflecting on their attitudes toward and relationships with those who suffer a schizophrenic illness.

## Structure of the Thesis

The thesis is presented in nine chapters. The Introduction sketches a broad background to the present study, and outlines the general purpose and aims of the research. The extensive nature of the literature in the field of schizophrenia in general has already been intimated. A selective approach to the vast literature on schizophrenia is taken in Chapter One in order to provide historical and contemporary backgrounds to the study and to explain the philosophical approach which underpins it.

Current and significant research into schizophrenia is reviewed and critiqued in Chapter Two, with the findings related to their implications for the person suffering from the illness. This chapter also deals with theoretical approaches to the care of those with schizophrenia, and includes reference to several works of fiction and autobiography in which mental illness is a central theme.

Chapter Three consists of a discussion of the phenomenological research approach and details the specific methods employed in this study.

In Chapters Four, Five, Six and Seven the study findings are presented and discussed. Each of these chapters deals with a specific concept from Martin Heidegger's (1927/1962) work "Being and Time," which, as will be explained in Chapter One, has provided an organising framework for the presentation of the data. Specifically, the discussion in Chapter Four deals with **Being-in-the-world**, Chapter Five with **Being-with-others**, and Chapters Six and Seven with particular aspects of the notion of **care** as it is described and explicated in Heidegger's writing. The meaning of each of these concepts and the way in which they are used to present the study findings is explained in the respective chapters.

Chapter Eight serves to summarise and integrate the study findings and to spell out the implications of the study for nursing practice, and finally in Chapter Nine, the study as a whole is reviewed, its boundaries identified and suggestions made for future research directions.

# CHAPTER ONE

## LITERATURE REVIEW PART I

## BACKGROUND

In using a phenomenological approach to the question "What is it like to live with schizophrenia?" the study draws on the writing of the German philosopher Martin Heidegger, particularly his early work "Being and Time" (Heidegger, 1927/1962). In their practice, nurses are fundamentally concerned with the lived experiences of health and illness (Leonard, 1989). Heideggerian phenomenology provides a philosophical analysis of the nature of human existence, of what it means to be a person, which offers a new way of approaching an understanding of what it means to live with illness.

I came to Heidegger's work during the early stages of this study when, having been introduced to the phenomenological approach to understanding nursing practice by authors such as Leonard (1989), Benner (1984, 1985), Benner and Wrubel (1989) and others, I felt the need to go back to the philosophical writing which underpinned their work. A review of the writing of several philosophers (including Merleau-Ponty, Marcel and Sartre) and others who had used phenomenological approaches to understanding psychiatric illness (Binswanger and Jaspers) left me decided that Heidegger's early work in "Being and Time" was particularly relevant and appealing in terms of its fit with the concepts and themes emerging during early data collection. As will be discussed in Chapter Three, I later discovered that many of Heidegger's central concepts could be used as a means of organising the data in this study and would be central to the discussion regarding implications for nursing practice.

This chapter begins with an introduction to Heidegger's work, which is significant to the study in two regards. It is relevant in terms of its implications for the method employed in the study and because the philosophical underpinnings of such an approach, in the form of Heidegger's discussion of fundamental ontology, form an important background to the study. Heidegger's propositions regarding what it means to be a person are central to an understanding of the phenomenological approach to research and therefore to the way in which the research question has been asked and answered in this study.

Thus an overview of Heidegger's contribution to our understanding of ontology is one dimension of the background to this study. His ideas are revisited in greater depth in relation to the data as they are presented. The other background components to the study are historical and contextual. Following the outline of Heidegger's central ideas regarding the nature of human existence, I will turn to a discussion of historical understandings of madness and the range of interpretations of mental illness demonstrated in the literature. The chapter ends with discussion about definitions of schizophrenia and identification of contemporary trends in the treatment of mental illness in New Zealand and overseas.

## HEIDEGGER'S FUNDAMENTAL ONTOLOGY

Heideggerian phenomenology centres around one fundamental question - the nature of Being. What does it mean to be? It is this question which is addressed in Heidegger's "Being and Time" (1927/1962), and which Heidegger describes as the most important metaphysical question, despite it being one which we have forgotten. Indeed Heidegger's position, in concentrating on ontology (what it is to be a person and how we know the world), rather than on the Cartesian epistemological question (how do we know what we know?) demands of us a new conceptualisation of personhood and of science, and has important implications for nursing (Leonard, 1989). In his philosophical writings Martin Heidegger presents an explanation of the way, as human beings, we find ourselves in the world, live with others and make meaning of our lives and our existence as a whole.

Heidegger's ideas are not easily absorbed. In part this is because of the demand they make in terms of an overthrow of our commonsense understandings of the world in which we live. In part it is also because of the difficulty of the language in which he presents his argument and his need to invent new terms in order that we might comprehend things in a new way. This difficulty is compounded for readers who rely on translations of the German work, in which Heidegger's neology loses some of its nuances. As a result his ideas have been regarded by some critics as inspired, whereas others see them as trivial and vacuous (Steiner, 1978). That ideas such as Heidegger's demand a new way of thinking about the world indicates that they are not the first line, commonsense notions with which we have become familiar through 300 years of Cartesian influence on thought and knowledge generation.

In this chapter I will outline the basic tenets of Heidegger's argument about Being, leaving more detailed explanations of some of the concepts, and the introduction of others, to the data chapters in which they are set alongside and illustrated by the data as discussion progresses. Because of the complexity of Heidegger's language, in introducing Heidegger's ideas at the outset of the study, where illustrative quotes are used they are largely from secondary sources (Guignon's 1993 collection of essays has been particularly valuable), though as the data are presented there is a heavier reliance placed on translations of the original work, especially "Being and Time."

## Being-in-the-world

Heidegger's work focuses on the nature of Being. Being itself, as Levin (1985, p. 11) explains, must be distinguished from the things that are: "Being is not *a* being, but rather the dimensionality within which all beings are to be encountered." Heidegger suggests that the first place in which we should look for the meaning of Being is in an analysis of Dasein, of human existence, of human being-in-the-world (Heidegger, 1927/1962). The word *Dasein* refers to human existence itself. Human beings hold a special place in the world, says Heidegger, because they are able to ask about the nature of existence, both conceptually and through their possession of language.

> The actual existence of man, his "human being" depends immediately and constantly on a questioning of Being. This questioning generates, it alone makes substantive and significant, what Heidegger calls *Existenz*. ... A being which questions Being, by first questioning its own Sein, is a *Da-Sein*. Man is man because he is a "being-there," an "is-there" (English will not weld the requisite amalgam). The ontic achieves *Da-Sein* by querying the ontological. It does so, uniquely and necessarily, by means of language.
>
> (Steiner, 1978, p. 80)

The nature of Dasein as Being-there indicates an essential dimension of Heidegger's argument, the situatedness of human existence in the world. Human existence is always worldly; it can be no other way, so that "the notion of existential identity and that of world are completely wedded" (Steiner, 1978, p. 83). As he explains

> *Dasein* is to be there (*da-sein*), and "there" is the world: the concrete, literal, actual, daily world. To be human is to be immersed, implanted, rooted in the earth, in the quotidian matter and matter-of-factness of the world ("human" has in it *humus*, the Latin for "earth").
>
> (Steiner, 1978, p. 81)

In this phenomenological view, the commonly held dualist perspective of the human being as mind and body can no longer hold. Dasein is always as-a-whole, and is located always in the world, not only in a spatial sense, but rather in an existential one. Dasein, as-a-whole, exists in-the-world.

In Heidegger's view we are not simply in the world as entities among a world of other entities, we are not things among other things (Stewart & Mikunas, 1974). Rather, Dasein, self and world are one.

> Dasein ... is defined as being-in-the-world. The hyphens, almost as awkward in German as they are in English, are indicative of the fact that, as Dasein, self and world are a unity. The world is not something external but is constituitive of Dasein. We are born into a world whose culture and history make us what we are. The Christian view that "we are in the world, but not of the world" is transformed. We are both in and of the world. "Worldliness" is an ontological property of Dasein; it is our context of involvements.
>
> (Dostal, 1993, p. 155)

This notion of world which is both constituitive of the self and constituted by the self is a fundamentally different one from the Cartesian idea of self as something that one "possesses." Heidegger's world is a priori. It is given in our history and in our cultural practices (Leonard, 1989, p. 43). Because Being-in-the-world is so commonplace and so unremarkable in the way that we live it, it is easy to overlook its centrality in terms of the nature of our existence (Steiner, 1978).

Because we are intimately and inseparably wedded to the world, there is, says Heidegger, no way for us to stand apart and see things "from the outside." This is phenomenology's fundamental point of departure from Cartesian thought. Rather than attempting to see things from a neutral and objective vantage point, Heidegger suggests that instead we ask Dasein about the nature of Being through enquiring into its everyday involvement in the world and though seeking to "uncover," to "bring to the light of day" that which has been concealed.

> In Heidegger's view, there is no pure, external vantage point to which we can retreat in order to get a disinterested, presuppositionless angle on things. So fundamental ontology begins with a description of the "phenomena" where this means what "shows itself," what "becomes manifest" or "shows forth" for us, in relation to our purposes as they are shaped by our forms of life. ... It is only because we are "always already" in on a way of life, engaged in everyday dealings with things in a familiar life-world, that we have some "preunderstanding" of what things are about. It is our being as participants in a shared practical world that first gives us a window onto ourselves and reality.
>
> (Guignon, 1993, p. 6)

## Temporality and Care

Clearly such a position has implications for phenomenology as a research method; this aspect of the philosophy will be addressed in more detail in Chapter Three. At this point, however, it is the implications for what it means to be a person that are of interest. Heidegger's writing concentrates on the nature of human existence in its everydayness. It is, he says, through our everyday dealings with things in the world, with other people, in our goals and projects, the intentions we hold and the way we live out our hopes and values, that we are defined. It is in this way that Heidegger introduces the notion of temporality to the nature of human existence. Dasein, he says, is *thrown* into existence. "It exists as an entity which has to be as it is and as it can be" (Heidegger, 1927/1962, p. 321). The notion of *thrownness* relates to the fact that we are already in the world, and that we are there as we are, in a world which "was not of our making but with which we are nonetheless stuck" (Hall, 1993, p. 137). In the world we are *thrown* into situations with certain possibilities and limitations. Heidegger refers to these limitations as Dasein's *facticity* (Guignon, 1993). Thrownness is also related to temporality:

> My past is nothing other than my "thrownness" - that is, my rootedness in a culture, my already established preferences, skills, habits, and so on - and it is precisely in terms of this thrownness that my present experiences get to be organised and endowed with a meaning.
>
> (Hoffman, 1993, p. 208)

Heidegger's view is not a fatalistic and deterministic one. Rather it posits that each of us is an individual, who must come up against history and the future in such a way that we make our own life according to our choices within certain limits which constrain us. We are shaped by cultural and historical understandings, but have a certain, situated, freedom within which to choose what we make of our lives. It is in making such choices on a day to day basis that we become what we will be seen to have been "in the end." It is only at the end of our lives that we will be seen as a whole, yet the whole is composed of all the day to day choices we make.

> Dasein's "being" or personal identity is defined by the stands it takes in acting in day-to-day situations over the course of its lifetime. Heidegger explains this by saying that Dasein is an "ability-to-be," which comes to realisation only through the ways it is channeled into concrete "possibilities," that is, into specific roles, relationships, personality traits, lifestyles, and so on, as these have been made accessible in its cultural context. ... My being - who I am - is nothing other than what unfolds in the course of my interactions with the world over the course of my life.
>
> (Guignon, 1993, p. 9)

Time, interpreted in this way, is no longer a linear matter. Rather, past, present and future each impact on the choices and possibilities with which Dasein is faced. As Krell (1977, p. 22) explains, "I pursue various possibilities for my future, bear the weight of my own past, and act or drift in the present. Of course at any given moment of my life all three structures are at play." There is a further dimension to Heidegger's analysis of temporality. In "Being and Time" he demonstrates that the *whole* of Dasein may be grasped in terms of his concept of *care*, from beginning (birth) to end (death) (Krell, 1977). Care (Heidegger's word is *Sorge*) signifies all of those things which matter to us, which concern us, to which our attention is turned, and includes solicitude for ourselves and others. As a central concept in the analysis of the data obtained in this study, care is further elaborated in Chapters Six and Seven.

## HEIDEGGER'S ONTOLOGY AND THE EXPERIENCE OF ILLNESS

Heidegger's writing includes reference to the nature of scientific thought. As he explains, although all science aims to investigate the intended object of its enquiry, there are times when theoretical explanations handed down through generations of scientific endeavour act to colour and cloud the way in which an enquiry is framed and therefore the kind of answer which may be obtained. In the investigation of human existence this is particularly relevant, given Heidegger's argument as to the nature of human being. The phenomenological approach, founded on the ontological question, is his remedy.

An excellent exposition of the way in which presuppositions and a different focus alter the understanding of illness is to be found in Toombs (1987), who writes:

> In discussing my illness with physicians, it has often seemed to me that we have been somehow talking at cross purposes, discussing different things, never quite reaching each other. This inability to communicate does not, for the most part, result from inattentiveness or insensitivity but from a fundamental disagreement about the nature of illness. Rather than representing a shared reality between us, illness represents in

> effect two quite distinct realities, the meaning of one being significantly and qualitatively different from the other.
>
> (Toombs, 1987, pp. 219-220)

As Toombs explains, to the physician an illness is a collection of signs and symptoms which together indicate a particular disease. He or she "thematises" the illness as being a particular case of this disease. The patient's reality is different. Rather than seeing illness as a disease process, patients experience the effects of the illness, and thus the illness itself, in terms of its impact on their everyday lives. "Thus, whereas the physician sees the patient's illness as a typical example of disease, the patient attends to the illness for its own sake" (Toombs, 1987, pp. 222-223).

Toombs' explanation sheds light on the different perspectives held by physician and patient, which are understandable in terms of Heidegger's explanation of what it means to be-in-the-world. In the situation described, the physician does not experience the illness personally, but rather comes across its symptoms in one about whom he cares, and in light of his desire, as physician, to make a diagnosis and to alleviate suffering or effect a cure. The patient on the other hand, experiences the illness immediately and at first hand. To him the effects on his everyday involvement in-the-world are paramount; indeed one might suggest that it is these effects which drive him to seek help from the physician in the first place. To presume that either position is the correct one is to negate Heidegger's argument. Rather, both positions simply reflect the nature of human existence and involvement in-the-world.

It is in this way that the work of Martin Heidegger has formed an essential backdrop to this study, for it is the Heideggerian standpoint from which the study was begun. As Heidegger (1927/1962) points out, each of us is thrown into the world in which certain possibilities are open to us and in which we are faced with certain limitations. Our world includes our history and our cultural orientations. Thus the understandings which society has and has had about mental illness colour the beliefs held by sufferers, families and professional carers. It is in a world shaped by historical and contemporary understandings that those who suffer from mental illness live.

## HISTORICAL CONCEPTIONS OF MENTAL ILLNESS

The legacy of understandings of mental illness which have come down to us over generations influence the ways in which we *are* towards those who suffer from mental illnesses. Such understandings also underlie assumptions that are held about what mental illness is and how it should be dealt with. It is for this reason that a brief discussion about historical conceptions of madness and its treatment is presented here as part of the background to the study.

There are assumptions about mental illness deeply rooted in our society. Barham and Hayward (1991, p. 2) refer to the work of Roy Porter, a medical historian who has written extensively on the social history of madness and psychiatric treatment, in their claim that "As social historians of madness have shown, we have inherited from the last century a deep disposition to see madness as essentially Other." Such an inheritance may be found not only in historical accounts but also in cultural media such as literature, art, newspapers, film and television. Recognition of their state of perceived difference is also to be found in the writings of the mentally ill themselves, who as Porter (1987a, p. 25) suggests "complain that 'alienness' is a false identity thrust upon them, or indeed a non-identity, a sense of being rendered a non-person." As Porter goes on to comment, this has readily become an excuse as to why the mentally ill should not be heard.

While it is tempting to conclude that nurses and other health professionals do not share this perception, in his work on the representations of disease Gilman (1988) emphasises the tendency for professionals to have incorporated understandings held by the wider society. "However much clinicians (not to mention the lay public) believe themselves to be free of such gross internal representations of difference, they are present, and they alter the relationship with the patient or client" (p. 48). In the case of schizophrenia he points out that visual images, which encapsulate a symbolic representation of social meaning, clearly depict the afflicted person as in some way other than the rest of society. In Gilman's analysis it is actually our own fear of collapse, of dissolution, which we in the Western tradition, as shown by our images of illness, project onto the world in order to have power over it. "Then it is not we who totter on the brink of collapse, but rather the Other. And it is an-Other who has already shown his or her vulnerability by having collapsed." (p. 1).

To a large extent the history of schizophrenia is subsumed under historical understandings of madness, especially prior to its recognition as a discrete mental illness. Porter (1987a, 1987b) traces Western conceptions of madness back to the ancient Greeks. Their contribution is related to the work of the Greek philosophers and playwrights, and also to the scientific medicine of the Hippocratic tradition. Thus understandings in Greek times rested on conceptualisations of mind and body, on the nature of man's place in the cosmos, and on his grasp of the possibilities of alleviating or curing disease. In essence the Greeks held two rival explanations; madness as badness or madness as disease, both of which "had a fearful potential for regarding the insane person as less than fully human" (Porter, 1987a, p. 13).

Porter's analysis suggests that even today we have not resolved the divide between the two Greek alternatives. A third explanation was added in medieval Christendom: madness as divine Providence. In Medieval times and during the Renaissance madness could be seen "as religious, as moral or as medical, as divine or diabolical, as good or bad" (Porter 1987a, p. 13). It seems that as a result of the Christian influence, the insane were seen as fellow human beings, God's creatures, and left relatively free to mix with the rest of society, although it is not clear from historical accounts what degree of care and protection was afforded them.

During the seventeenth and into the nineteenth and twentieth centuries the separation of the mad from the rest of society became common. The history of the treatment of the insane during this period is complex. As Bynum, Porter and Shepherd (1985, p. 2) point out, even the recording of history in this sphere is fraught with the difficulties inherent in the definition of mental illness, the social meanings of treatment of the insane, the teasing out of "hidden interests and latent social functions." Revisionist histories, such as those of Michel Foucault (1961/1965) take issue with more traditional accounts, yet Foucault's work itself is now the subject of criticism by social historians such as Sedgwick (1981) and Porter (1987a, 1987b).

Most such criticisms relate to the sweeping condemnation of the asylum movement made by Foucault, but there is also a suggestion that his work has done little to aid the plight of the mentally ill themselves. In his critique of Foucault's "anti-history of psychiatry," Sedgwick (1981) claims that protagonists of the anti-psychiatry school (those who suggest that psychiatry is purely a mechanism of social control, or that mental illness does not exist, or both), along with many of the psychiatrists they criticise, have a part to play in perpetuating the idea of difference in the mentally ill. "The mythology of madness which is canvassed by many psychiatrists as well as by anti-psychiatrists has the unfortunate effect of reinforcing a blanket judgement whereby mad people, saintly or awkward, persecuted or treated, are seen as mad all the time" (p. 246). He supports this claim by reference to the fact that Foucault does not give an account of any recognisable psychological syndrome, but rather concentrates on stereotypes which he himself identified as unsatisfactory.

Porter, on whose work I will rely here, suggests that the practice of asylum arose as a policy of exclusion of those "displaying delinquent and dangerous traits" (1987a, p. 13). The main reason for confinement was dangerousness rather than psychiatric benefit, although there is also evidence that the keeping of a madhouse was financially lucrative and beneficial for a medical career (Porter, 1987b). From the seventeenth century onwards, the mentally ill were increasingly held segregated from the wider society. While it is common to read about the oppressive conditions in many of these institutions, not all historians view the movement as entirely bad:

> It is an open question whether the lunatic confined to a madhouse in 1650, 1750 or 1850 got a rougher deal than his non-Bedlamite brother still permitted to haunt the hedgerows, or chained up in a barn, or kept, like Mrs Rochester in "Jane Eyre," locked away in the attic. And it would, in any case, be a mistake to depict the movement to institutionalise the mad as essentially repressive and punitive. What it principally was, was segregative. Its rationale first and foremost expressed the notion that locking up the mad was best for everyone, essential both for the wellbeing of the lunatic and for the safety of society.
>
> (Porter 1987a, p. 17)

During the mid-eighteenth century a new faith in cure for the insane arose. Specific forms of treatment included drug therapies, physical and mechanical treatments and then the appeal to reason and transformation of behaviour. This latter heritage was in part based on the work of Locke, whose concept of the human mind as a tabula rasa, and the suggestion of insanity as erroneous thinking, lead to the conviction that the insane might be treated like children, re-educated and thus reconditioned for a civilised life. Doctors in the asylums began to develop a specialist form of medicine, based firmly in the asylum movement. Procedures and therapies such as the use of purgatives, bloodletting, electric shocks, cold baths, confinement in dark rooms offered new hope of cure and the revival of "the dormant humanity of the mad" (Porter 1987a, p.19).

There are disturbing parallels with these forms of treatment to be found in the descriptions of some mid-twentieth century authors (Frame's 1961 work includes examples which will be discussed further in the following chapter) and in the accounts of one of the participants in the present study, who first became ill and was hospitalised in New Zealand some four decades ago.

At the end of the eighteenth century, the reformers of psychiatry, among them Pinel, Tuke and Chiarugi, aspired to treat their charges as potentially curable human beings. A quiet revolution in the treatment of the mentally ill was begun virtually simultaneously in France, Britain and Italy. The York Retreat, founded by a group of Quakers led by William Tuke is one example, and well documented in Porter's (1987b) publication. The Retreat was a successful programme run as a spiritually close community where treatment was moral rather than medical, friendly rather than frightening. The actions of these reformers "reflected enlightened ideas of illness and individual liberty" (Weissberg, 1991, p. 317).

The success of reforms such as those of the Retreat reinforced the idea that asylums were right for the mad and the promise of cure lead to an overwhelming increase in the numbers of people locked away in care. Unfortunately the exceptional conditions which existed at the original birthplaces of reform were not carried over to other institutions. There was no regulation of small size, a homogeneous community or a population of acutely unwell rather than chronically ill, senile or alcoholic patients (as was found, for instance at York), and the consequent failure of this promised return to normalcy for the majority of the population in the asylums lead to a belief in insanity as, after all, incurable, a degenerative condition (Porter, 1987b). This, in turn, leant weight to the medical theories of insanity as "ingrained physical disease, perhaps even a hereditary taint, a constitutional diathesis, a blot on the brain." Porter (1987a, p. 20)[1]

Once again there was reason to see the mentally ill as different, as other than the rest of "normal" society. Barham (1992, p. xiii) suggests that despite the best intentions of mental hospital reformers and the variety of forms of institution which have developed, mental hospitals still carry the heavy burden of stigma which has always been attached to them. He posits that "the legacy of the Victorian asylum is, in an important sense, the abolition of the *person* who suffers from mental illness." Instead, Barham argues, we are left with "mental patients, their identities permanently spoiled, exiled in the space of their illness on the margins of society."

One of the effects of segregating the mentally ill from the wider society was to effectively remove their voice as one that might be either heard or understood. "The more the mad were locked away, the more they were 'shut up' in every sense of the term." (Porter 1987a, p. 31) Not all of this silencing was unintentional. During the seventeenth, eighteenth and nineteenth centuries the talk of the mad was believed to be gibberish, to hold no real communication, no real truth. This belief reached its peak for those with schizophrenia when Kraeplin described the disease **dementia praecox** around the turn of the century (it was named **schizophrenia** by Bleuler shortly afterward). Kraeplin is quoted by Porter (1987a, p. 34) "The patients become monosyllabic, sparing of their words, speak hesitatingly, suddenly mute, never relate anything on their own initiative. ...They enter into no relations with other people." This, says Porter, "brought into focus one of the inchoate tendencies of emerging psychiatry, the notion that madness's essence lies in being alien, different, other."

While Porter may be correct in his interpretation of the effect of these ideas, it should be emphasised that Eugen Bleuler, whose work was translated into English only in 1950, was actually in favour of avoiding hospitalisation for those with schizophrenia.

---

[1] The similarity of this hypothesis with that of some current writers working from a biological base is clear, although the latter, fortunately, tend to have more optimistic outlooks.

> The institution as such does not cure the disease. However, it may be valuable from an educational viewpoint and it may alleviate acute, agitated states due to psychic influences. At the same time it carries with it the danger that the patient may become too estranged from normal life, and also that the relatives get accustomed to the idea of the institution. ... In general, it is preferable to treat these patients under their usual conditions and within their habitual surroundings.
>
> (Bleuler, 1911/1950, p. 475)

At the turn of the century Freud and the other leaders of the new dynamic psychiatry promised a new therapeutic innovation, the talking cure, at least for the less seriously stricken members of the mentally ill population (Porter, 1987a). However, the cure was recommended by Freud himself as being suitable only for those with a neurotic illness; people with schizophrenia were still not to be heard in an intentionally therapeutic way.

Two major reforms are recorded in the history of what by now had become "psychiatry" in the twentieth century; the mental hygiene movement and the psychopathic hospital in the early twentieth century, and the community mental health movement in the middle of the century. The mental hygiene movement was particularly evident in the United States of America where the work of Adolf Meyer, reinforced by the development of psychoanalysis, led to a new optimism about the prospect of scientific psychiatry and the promise of cure for many patients. While the effect of this movement was small in terms of effecting cures for numbers of patients, it did lead to an expansion of the boundaries of psychiatric practice to include other social problems, and it resulted in the development of other occupational groups such as psychiatric social work, clinical psychology, and pastoral counselling (Morrissey & Goldman, 1984). The influence of the movement can be seen in the parallel development of multidisciplinary teams in New Zealand.

World War II marked the beginning of what is the currently the most significant change in the treatment of the mentally ill. The number of American draftees found mentally unfit to serve in the forces suggested a higher level of psychopathology in the general public than had previously been recognised, and military psychiatrists began to study situational stress and brief hospitalisation (Johnson, 1990). The discovery of new psychotropic medications coincided with the new enthusiasm for brief treatment methods and enabled doctors to avoid the removal of the mentally ill to faraway hospitals (Morrissey & Goldman, 1984). Mental health legislation in many parts of the world over the past 40 years has supported the move toward community care rather than hospitalisation. Reforms have included support systems and rehabilitation for the chronically mentally ill. The ideology which accompanies such moves has included concepts such as accessibility to a comprehensive range of services and continuing care (Anthony & Liberman, 1986).

The reforms have not been without their critics or their problems. Prejudice still runs high in many countries, support services have not always been suitable or available and in many places health professionals and the public are concerned about homelessness among the chronically mentally ill (Johnson, 1990). Goldman and Morrissey (1985) conclude that there is now a fourth cycle of reform emerging to respond to the failures of deinstitutionalisation and community mental health in the USA. The authors suggest that this new reform is targeted at meeting the needs of the chronically mentally ill in recognising that these encompass areas traditionally dealt with by public health and social welfare. The shrinking resource budget for these services, however, poses a real threat to the possibilities of success in this latest reform.

In spite of the good intentions behind the movement toward deinstitutionalisation and community care, progress depends to a large extent on reshaping attitudes toward those suffering from mental illness (Barham, 1992). Even today the reactions of society to those considered mentally ill remain coloured by commonplace beliefs, superstitions and prejudice. Evidence of the stigma faced by the mentally ill in New Zealand can be found in recent writings and speeches by the growing "psychiatric consumer" movement (e.g. O'Hagan, 1989a). Disley (1989, p. 8) cites New Zealand research which backs her claim that

> Even now, with the dawning of the 1990's, mental illness is unduly regarded as outside "the norm" and both individuals with an illness and the professional field suffer from the effect of stigma. The majority of people hold ill-informed opinions and attitudes toward the area of mental ill health.

As will be demonstrated in the chapters which deal with the findings of this study, the effect of both public and professional attitudes toward those who have suffered a severe mental illness can be deeply disturbing and have a significant effect on the subsequent shaping of their lives.

Also apparent throughout this century has been the emergence of a spectrum of theoretical models of mental illness in general, and/or schizophrenia in particular and it is to these that the discussion now turns. As will be shown in Chapter Two, many of these models influence the nursing literature today. Whether consciously articulated or held as unstated "givens," they form the basis of clinical decision-making and interdisciplinary communication and colour nursing perceptions of the person with a schizophrenic illness. In effect theoretical models provide the background from which health professionals practice, whether or not they are conscious of the origins or limitations of these ideas. As such they form another dimension of the background to this study and are particularly relevant to discussion of the study findings, detailed in Chapter Eight.

## MODELS OF MENTAL ILLNESS

Siegler and Osmond, in work, some of which is now almost 30 years old, presented what are still among the most useful summaries of the various models of schizophrenia which underlie the twentieth century debate concerning the nature and appropriate treatment of this baffling illness (Siegler & Osmond, 1966, 1974; Siegler, Osmond & Mann, 1969).

Today the models described by Siegler and Osmond are no longer considered scientifically credible as independent and competing perspectives. A new model which incorporates stress and vulnerability - the stress-diathesis view - is now widely accepted amongst clinicians and researchers as offering a more comprehensive and fitting base for understanding schizophrenia. A brief, and admittedly simplified, description of this and the models identified by Siegler and Osmond follows. Their importance lies not in their proposed ability to explain the pathology of the illness, but in the way they influence the thinking of clinicians, researchers and the public, either consciously or unconsciously. In some way many of the models have shaped nursing and other health care practice, and continue to do so, even when the models themselves are no longer wholly acceptable.

Siegler and Osmond (1974) propose that there are eight models of mental illness: medical, moral, psychoanalytic, family interaction, conspiratorial, social, psychedelic and impaired models. In their opinion there is a serious incompatibility amongst these models. They further suggest that this incompatibility has given rise to the lack of consensus regarding the nature of schizophrenia, and its appropriate treatment, found amongst health care workers, the lay public, the media and sufferers themselves. An alternative view is that the lack of consensus regarding the nature of the illness is the origin rather than the result of conflicting models. This argument recognises some of the models as incompatible, and sees others as having rather indefinite boundaries, so that there is an almost imperceptible merging.

In Siegler and Osmond's view one of the models, the medical model, is superior to the others. As the examples of most recent research into schizophrenia will show, this is a position which is gaining popularity amongst many disciplines, although renamed as a biological or biomedical model. The nursing literature, however, has only recently taken notice of the move toward this model. It may be that nursing's approach to health and illness, which requires dealing with the whole person in context, is relatively untroubled by the proliferation of models from other disciplines. Certainly little evidence was found in the nursing literature of writing which signalled alarm in the way that it is registered in the psychiatric press. McLaren (1992) for example, agrees with Siegler and Osmond's position that at least three; the psychoanalytic, behaviourist and "organic" or biological models are incompatible views of the same subject. The importance of their incompatibility lies in the fact that methods of treatment which are congruent with one model may, in fact, be quite inappropriate in another, while the attitude with which a patient is approached may be subtly different, depending on the model of mental illness held by the health professional(s) concerned.

In the biomedical model, the patient is considered to be sick. Although unknown, the cause of the illness is assumed to be a natural one, something which "just happens." Once a diagnosis is made, treatment and prognosis can be determined. Treatment is specific for the particular illness, and prescribed by a doctor; care may be given by nurses, and other staff may assist with the patient's rehabilitation. While the specific aetiology of schizophrenia is not known and there is, as yet, no cure, it is hoped that both dimensions will eventually be understood. Society is expected to be sympathetic and kind towards its mentally ill, to use public funds for facilities for their care, and may also expect to be protected from anyone who is dangerous, in just the same way as it might be protected against those who are infectious.

The moral model incorporates two dimensions; a religious and a behavioural one. In this model it is the behaviour of the patient which causes concern, violating social mores, as it does, in times of psychosis. There is no illness, rather it is the behaviour of the person which is requiring of correction or re-education. Such behaviour is taken at face value, rather than being interpreted, and it is the aim of the therapist to find ways of having the patient take responsibility for his or her behaviour until it matches that acceptable to society. This is a model, at least in its religious form, little in vogue in the literature today, although it was the philosophical mainstay of the moral therapy movement in the nineteenth century.

In the impaired model, the person is considered to be permanently disabled by his or her condition. Society is expected to be kind towards such persons, while the main aim of therapy is toward rehabilitation and protection from exploitation, abuse, or persecution. Unrealistic hope should not be offered, although the person should be encouraged to lead as normal a life as possible within his or her limitations. While not based solely on it, the practice of psychiatric rehabilitation which has grown with the community mental health movement incorporates some aspects of this model, combining them with elements of the psychoanalytic model (Anthony, Cohen & Cohen, 1983).

The psychoanalytic model concentrates on the aetiology of emotional difficulty. It is presumed that a person suffering from a psychosis has undergone some traumatic early experience, or "has failed to negotiate some critical stage of emotional development" (Siegler & Osmond, 1966, p. 1197). The origin of a patient's illness is discovered through history-taking, the analysis of dreams, free association and other psychoanalytic techniques. All behaviour is to be interpreted symbolically by the therapist who is the key player in the treatment programme, one which is dependent on transference between patient and therapist. A patient is considered well when he or she has insight into his or her problems, as they have been reflected in behaviour.

In the family interaction model, it is the entire family, not just the identified patient, who is sick. The patient is indeed carrying the illness of the group. Group therapy with the whole family encourages change in the family system, thus releasing the pressure on the sick individual, and enhancing the functioning of the entire family system. Recent developments in helping families develop uncritical problem solving skills (eg. Falloon, 1985), may be seen to rely in part on this model.

The conspiratorial model takes two forms. It either calls attention to the inhumane treatment often received by the mentally ill (as in Goffman's 1961 analysis) or suggests, as does Szasz (1971) that there is no such thing as mental illness at all. The mentally ill are really the victims of labelling by the wider society which cannot tolerate deviance. Foucault's (1961/1965) work could be classed as an example of the conspiratorial model.

The social model holds that mental illness is a reflection of the malfunctioning of society: a "sick" society produces mentally ill members. Mental illness is also an aspect of poverty and discrimination. Siegler and Osmond (1966) contend that social models are usually put forward by epidemiologists who have analysed differences in subpopulations and individuals which might make them susceptible to mental illness. They also discuss a "folk" version of this model which equates poverty with mental illness. In this analysis, social, political and economic improvement of the mentally ill and their families would constitute successful treatment. In a healthy society, families would be able to rear children without mental illness. The fourth cycle of reform in community care of the mentally ill identified by Goldman and Morrissey (1985) and discussed on p. 23 contains elements of this model, as does the work of Barham (1992).

The psychedelic model is attributed largely to R. D. Laing, who in Siegler and Osmond's (1974) view, sought to romanticise schizophrenia by drawing parallels with the rebelliousness of the young and their desire for a new and different world. The psychedelic model is described as a view of madness "that the mad see things more clearly than the rest of us, that madness is a mind-expanding 'trip', and that the burden of the misunderstanding about madness lies at the doorstep of the so-called sane" (Siegler & Osmond, 1974, p. 58). In this model it is presumed that schizophrenic sufferers have been driven mad by their families, and that their behaviour is an attempt to escape the bind in which they find themselves. Treatment consists of a guided trip into madness and out again, as a result of which the person may find enlightenment.

The contribution of R.D. Laing to our understanding of schizophrenia is more complex than this reference by Siegler and Osmond suggests. In his work Laing suggested a radical rethinking of the nature of mental illness, schizophrenia in particular, arguing with co-author Esterson in "Sanity, Madness and the Family" (1964) for instance, that what had traditionally been seen as "illness" was actually a manifestation of behaviour by which people managed to live in intolerable family situations. As such the behaviour of those diagnosed as "schizophrenic" is not meaningless, but rather quite intelligible in light of the network of his or her family relationships.

As was indicated earlier, in recent years a further model of schizophrenia has evolved, largely as a result of research into the biological factors involved in the illness. The stress-vulnerability model was developed to account for the fact that biological factors may be necessary but not sufficient for the illness to occur. This model explains the susceptibility of people to the illness as being multifactorial in those who are vulnerable, and accounts for periods of relapse in sufferers who have been well but relapse when subject to environmental stress. An excellent review article is provided by Yank, Bentley and Hargrove (1993), and the discussion will be picked up again in Chapter Two.

## THE NEED TO RECOGNISE THE *PERSON* WITH THE ILLNESS

The diversity of views which have been brought to bear on schizophrenia is both striking and troubling. As Flack, Miller and Wiener (1991, p. 251) put it

> Schizophrenia has been a subject of constant study to which a massive amount of time, effort and fiscal resources have been dedicated. Almost one hundred years of effort, aimed at clarifying the figure-ground of the phenomena subsumed under this category, has resulted in far less clarity or immediate help than efforts in most other kinds of endeavour.

Many authors have lately made reference to this confusion and have begun to point out the need to attend to the effect of the illness on those who suffer from it, as well as indulging in research or theorising which looks at one area of the debate in particular. Theoretical views drive research directions, and the rise in interest in biological research has lead some authors to caution that a swing too much in this direction may result in a view of mental illness in which the person is lost. There is an increasing recognition of the need for complex constructs which will allow clinicians and researchers to integrate psychological, biological and social factors in their impact on human functioning (Lipowski, 1989; Strauss, 1992). Hartmann (1992) emphasises the need for humane values to underlie perceptions of mental illness, and goes so far as to suggest that quantitative studies may have a part to play in such values being lost from sight. He stresses the need to deal with "whole people in context and over time" (p. 1137).

There is a growing literature which acknowledges the disability which a schizophrenic illness may bring. One of the most prolific and sympathetic authors in this field is Bachrach, whose work focuses largely on the chronically mentally ill, and indeed on the meaning of chronicity for this population. Bachrach (1986, p. 981) says: "Undoubtedly one of the major benefits of deinstitutionalisation programming is our growing understanding of the chronically mentally ill as individuals who have disabilities that transcend and complicate their illnesses." She describes three levels of disability typically endured by the mentally ill; firstly, psychiatric impairments or dysfunctions considered symptoms of the illness; secondly, adverse personal reactions which stem from the experience of the illness rather than result from the illness itself, and thirdly, social disablements, such as stigma, poverty or unemployment which result from societal responses to illness and disability. Bachrach's analysis is not far removed from the reports of Birchwood, Hallett and Preston (1988, p. 14) of the "tragic impact" which schizophrenia may have on an individual's mental, emotional and social life, or what Jaspers (1913/1963, p. 284) referred to as "the grim daily struggle" faced by many people with schizophrenia in periods between health and collapse.

The deinstitutionalisation movement and its attendant notions of community care have emphasised the need to take notice of individual differences in needs and to people's quality of life (Bachrach, 1988), while the need to learn more about the ways in which people with schizophrenia learn to cope with their symptoms is identified as an important area for research (WHO, 1991). This study was undertaken in an attempt to better understand the everyday lives, difficulties and coping strategies of people who live with schizophrenia in the New Zealand community.

## THE DIAGNOSIS OF SCHIZOPHRENIA

First described as a discrete category of illness by Emil Kraeplin in 1896, then renamed schizophrenia by Eugen Bleuler (1911/1950), the concept of schizophrenia is almost universally accepted but it remains ill-defined (Andreasen, 1987). The literature still contains much reference to the need to clarify diagnostic criteria, define characteristics of the illness,[2] and delineate symptoms of schizophrenia from those of affective disorder (eg. Taylor, 1992).

The most prevalent means by which a psychiatric diagnosis is arrived at in New Zealand is through the application of the diagnostic criteria set out in the DSM-III-R[3] The introductory description of schizophrenia contained in the manual (the full description is several pages long) is given below:

> The essential features of this disorder are the presence of characteristic psychotic symptoms during the active phase of the illness and functioning below the highest level previously achieved (in children or adolescents, failure to achieve the expected level of social development), and a duration of at least six months that may include characteristic prodromal or residual symptoms. At some phase of the illness schizophrenia always involves delusions, hallucinations, or certain characteristic disturbances in affect and the form of thought. The diagnosis is made only when it cannot be established that an organic factor initiated and maintained the disturbance.
>
> (DSM-III-R, 1987, p. 187)

---

[2] Writers such as Andreasen and others refer to the identification of defining features of a disorder as its "phenomenology" a term which needs to be distinguished from the philosophical term phenomenology used in this study.

[3] Diagnostic and Statistical Manual of Mental Disorders (Third Edition - Revised). The abbreviated form DSM-III-R is its common name. Toward the conclusion of the study the DSM-IV (Fourth Edition) was published (1994).

A deteriorating course is not necessarily assumed for diagnosis under these criteria, although a minimum time of illness is required. The manual cautions practitioners to take cultural factors into account when making a diagnosis and also makes a statement about the atheoretical nature of its definitions. The statement points out that for most of the disorders contained in the manual, aetiology is unknown, although many theories have been advanced and "buttressed by evidence - not always convincing" (American Psychiatric Association, 1987, xxiii). Given the impossibility of presenting all possible aetiological theories for the disorders in the manual, and the desire to produce a tool which is useful to clinicians of many different theoretical persuasions, the authors state that it was considered ideal not to attempt to situate the criteria in any theoretical context. Thus it is believed that the manual may be used equally effectively for diagnostic purposes by those with, for example, a medical, psychoanalytic, or behavioural perspective.

It is also common to find reference in the literature to "positive" and "negative" symptoms displayed in schizophrenia. Torrey (1988) suggests that there may actually be two subtypes of the illness, each characterised by the predominance of either positive or negative symptoms. Positive symptoms are those which are present but which should not be, such as delusions, hallucinations and thought disorders, e.g. loose associations. Negative symptoms are those which indicate an absence of attributes which should be present, and include for example, poverty of speech, apathy, social withdrawal, lack of drive and blunting of emotions (Torrey, 1988).

It is often suggested that approximately one percent of the population suffers from a schizophrenic illness at some time during their lives (M. Abbott, 1992; Andreasen, 1984; Bleuler, 1991; Cleghorn & Lee, 1991; Torrey, 1988). However this figure is debated and the "true" incidence of the disorder is difficult to measure given the problems already referred to in the definition of the concept itself and in the absence of objective disease markers (Jablensky, 1993). It does appear that rates of incidence are similar across cultures and that there is a significant genetic transmission of characteristics which predate overt illness manifestation. It is also known that while men are more at risk between the ages of 15 and 24, women "catch up" and exhibit a higher first incidence over the age of 40. The illness seems to take a more disabling course in men than in women, and men also show a higher incidence of discernible brain abnormalities than do women (Jablensky, 1993; Seeman, 1986).

In concert with those authors calling for a return to a focus on the person rather than the illness, the literature is beginning to include a number of articles emphasising the role of diagnosis as being one of classification, not of grasping some ultimate reality (eg. Ellard, 1992). Similarly, a new look at prognosis is suggesting that many fewer people with schizophrenia may go on to a course of permanent illness than was previously accepted.

> The focus has been shifted back from the disorder to the person, who is seen as a vulnerable human being living a life with intermittent episodes of schizophrenia. These episodes may taper off across time, as the person gathers his/her energies to redevelop and improve levels of basic functioning such as self-care, work, and social relations.
>
> (Harding, Zubin & Strauss, 1992, p. 34)

Some researchers have suggested that schizophrenia may be disappearing as an illness, but an alternative explanation is that the apparent fall in incidence is more likely caused by changes in treatment modalities (including less hospitalisation) and the tightening of diagnostic criteria (Horgan, 1990; Jablensky, 1993). It seems that at least for the forseeable future a significant proportion of the population will continue to struggle with the effects of schizophrenic illness on their lives.

## THE CONTEMPORARY NEW ZEALAND SCENE

Although a brief hospital stay is not uncommon during the acute phase, most people who develop a schizophrenic illness in New Zealand are cared for primarily in the community, with medication the main form of treatment. Here the development of psychiatric hospitals away from the main cities, followed by the trend toward closure of these institutions and reliance on acute psychiatric units attached to general hospitals, has largely followed patterns in Britain and the USA. The greatest in-patient population for New Zealand psychiatric hospitals was recorded in 1944, indicating that deinstitutionalisation, and a move toward community care, is not a recent trend in this country (Boddy, 1992). Whether the funds freed by the closing of psychiatric hospitals have been redirected into the community and to what end, is a matter of political debate, and of concern to many clinicians in the mental health field.

Services are not uniform across the country as recent changes in the structuring of health care services have meant a planned decentralisation of services, and a reliance instead on regional programmes. In theory at least, community consultation is undertaken regarding service needs and delivery. Four Regional Health Authorities currently fund and oversee the provision of all health services, mental health services having been identified as a priority area (National Committee on Core Health and Disability Services, 1992).

While homelessness is documented as a concern for the mentally ill in many countries (eg. Aiken, 1987; Chafetz, 1990; Goldman & Morrissey, 1985; Johnson, 1990) it is rarely reported as a problem in New Zealand although their accommodation is often less than ideal. On the positive side, in the past few years a growing number of community housing trusts have been established, and in many areas these are providing well supervised housing for those in need, using consultative planning in their development (eg. Haxell, 1992). Genuine concern regarding the availability of psychiatric assistance for people who become unwell in the community is kept alive by media reports, and the fear of violence by "ex-psychiatric patients" has been fuelled by a small number of tragic episodes. There is uncertainty amongst the public as to whether funding in the community is sufficient for the needs of the mentally ill. Meanwhile a growing consumer movement lead by "psychiatric survivors" aims at countering prejudice, and is working toward greater consumer input into service provision and quality assurance (O'Hagan, 1989b).

In New Zealand approximately twelve percent of the population is Maori. Figures for psychiatric hospital admissions show disproportionate rates for Maori when compared with non-Maori, and there is recognition that Maori people have been more likely to be admitted to psychiatric units or hospitals following referral from non-medical agencies (eg. from law enforcement agencies). In 1988 Maori rates of admission for schizophrenic psychoses were twice the non-Maori rate for men and 2.8 times higher for women (Pomare & de Boer, 1988). It is recognised that psychiatric hospital admissions do not tell the whole story regarding mental health or illness, and will tell even less as more hospitals are closed. The need to attend to the social, cultural and economic factors involved in this context is becoming increasingly apparent. Needed changes in the provision of mental health services for Maori have been identified by Maori and recognised by Government (Minister of Health, 1992). Maori liaison workers have been appointed to work in most service areas, and separate Maori units were established alongside some psychiatric hospitals, notably Te Whai Ora at Tokanui Hospital, Te Awamutu. Primary health care remains the biggest hope for mental health. The growing recognition of New Zealand as a bicultural nation includes more possibilities for appropriate services run by Maori for Maori. "Managed care, with active outreach programmes for Maori, by Maori, offers the potential for new levels of primary health care based on the obligations of *whanau* (family) and *iwi* (tribe) rather then the detached goodwill of benign professionals." (Durie, 1994)

In my initial plans for the conduct of this study I did not seek either to include or exclude Maori participants. It so happened that only one participant claimed any Maori descent, and she identified primarily as paheka.[4] Discussion in Chapter Nine will refer to the lack of cultural mix of the study participants and discuss the implications of the study for future research in this area.

## REVIEW AND SUMMARY

In this chapter discussion has included several aspects of the background to the study. An overview of Heidegger's work on the nature of Being and its implications for what it means to be a person has explained the philosophical context of the study and provides an outline of the concepts which will be revisited when the data are presented and discussed in Chapters Four, Five, Six and Seven. The impact of historical understandings of schizophrenia on our tendency to see the mentally ill as Other has been presented. Since, in Heidegger's view, our history and culture help shape our present understandings and choices, it is important that historical conceptualisations of schizophrenia are borne in mind as background to the study.

As a result of knowledge developments over the past century, and influenced by various treatment modalities and philosophical positions, several different theoretical models of mental illness have evolved. Many of these are in current use, and an outline of nine such models has been presented, along with brief discussion as to their implications in practice. These models form an often unstated background to clinical decisions and influence attitudes toward the mentally ill themselves. Contemporary directions in the provision of services for

---

[4] A New Zealander of non-Maori descent, usually Caucasian

the mentally ill have then been outlined, since it is in this context that the study was carried out.

In the next chapter discussion turns to research relevant to the study. Such work includes research into the aetiology and treatment of schizophrenia, research which examines effective interventions for those with the illness, and studies which have examined the subjective experience of schizophrenia. In addition, relevant nursing literature which indicates theoretical outlooks on schizophrenia will be discussed, and mention will be made of a selection of fictional and autobiographical accounts of schizophrenic illness.

# CHAPTER TWO

# LITERATURE REVIEW PART II

There is widespread acceptance amongst writers and researchers in the field that the contemporary literature dealing with schizophrenia is both vast and fragmented. One author recently went so far as to suggest that schizophrenia had "gained the reputation of a graveyard of research" since "few findings stand the test of time, most of the pieces of this particular jigsaw seem to be missing, and it is not easy to make sense of those that are available" (Mortimer, 1992, p. 293). In undertaking the present study I have been aware both of the huge volume of the literature which deals with aspects of schizophrenia and of the paucity of work which relates to the subjective experience of those who live with a schizophrenic illness. In this chapter my intent is to situate the present study in the context of current research trends and findings and to discuss fictional, autobiographical and research writing concerning the experience of schizophrenia. The focus of the chapter is on nursing literature and research and other writing which addresses the subjective experience of schizophrenic illness. However, research into other aspects such as aetiology, neuropsychology, neurophysiology and treatment of the illness form an essential background from which understanding of the complexity of the illness can proceed, while they also impact directly on the nature of informed nursing practice. It is with a selective overview of these aspects and some related research areas that the chapter begins.

## THE NATURE AND INCIDENCE OF SCHIZOPHRENIA

### Epidemiology

Some elements of the epidemiology of schizophrenia namely incidence, age of onset and gender differences, were mentioned in Chapter One. Jablensky (1993) presents a review of the latest findings and suggests that there is strong support for conclusions related to incidence across population groups, to a genetic component in the transmission of the disorder and to the course and outcome of the illness under certain situations.

> Epidemiological evidence now provides strong support for the conclusion that schizophrenia: first, occurs universally and has similar manifestations and age and sex patterns in different populations; second, is associated with a significant genetic transmission of characteristics which may antedate manifest psychotic symptoms; and third, has a course and outcome that can be predicted within certain confidence limits by a relatively small number of variables.
>
> (Jablensky, 1993, p. 50).

It appears that people who live in developing countries may expect a better outcome than those in developed countries, that some subtypes are predictive of a better outcome than others, and that those with a predominance of positive symptoms fare better than those with more negative symptoms. Males, those with poor adolescent adjustment, and cannabis users are also less likely to demonstrate a good outcome (Jablensky, 1993). However, the nature and extent of respective contributions made by genetics, neurodevelopment and environment to what is an unequivocally complex aetiology are still unknown.

## Aetiology

A summary of theoretical models which have been proposed regarding the nature and causes of schizophrenia was presented in the previous chapter. Current aetiological research in the psychiatric literature is focused largely on epidemiological and biological factors (Sharma & Murray, 1993), while psychosocial factors (once thought to be the basis of the development of schizophrenic illness) are now more commonly researched in relation to treatment and outcome.

Sharma and Murray (1993) present a review of aetiological theories in schizophrenia. Twin and family studies suggest a considerable genetic influence in the transmission of the illness. The above authors cite a study by McGue (1992) who suggests that between 60 and 70 per cent of the variance in susceptibility to schizophrenia is heritable and conclude that this "probably represents a view which would gain the maximum degree of support from contemporary researchers" (Sharma & Murray, 1993, p. 80). There is evidence that paranoid schizophrenia is less influenced by a genetic component than is non-paranoid illness.

Since it is known that some environmental factors must be involved in the genesis of schizophrenia, researchers continue to identify possible environmental triggers. An ongoing research question concerns the possibility of environmental exposure in utero to some hazardous factor influencing the later development of schizophrenia. The finding that there is an association between season of birth and schizophrenic illness (more babies born in late winter and spring develop schizophrenia later in life) has lead to research into the possibility that some form of constitutional damage, hypothesised to be a subtle brain damage, occurs to these children. One possibility is prenatal exposure to influenza, a number of studies having been conducted on data concerning influenza epidemics. As Sharma and Murray (1993, p. 81) conclude, "the relationship of prenatal influenza to risk of schizophrenia remains at the level of an epidemiological association without a satisfactory explanatory mechanism." However, if some kind of viral agent does play a role in the prenatal aetiology of schizophrenia, it would be expected that schizophrenia would be more common in those born in the cities where respiratory viruses are more rapidly and successfully spread, an hypothesis which has been supported by some recent research in England and Wales (Takei, Sham, O'Callaghan & Murray, 1992 cited in Sharma & Murray, 1993).

Other possible prenatal and perinatal factors which might influence the development of schizophrenia have been explored in recent research. One interesting study reported by Sharma and Murray (1993) found no more obstetric complications among people with schizophrenia-like psychosis than among controls, but they did report an increased frequency of thyroid disease among the parents, particularly the mothers, of those with schizophrenia. The researchers, de Lisi et al (1991), speculate as to the possibility that an endocrine abnormality during pregnancy might have impaired foetal brain development. Sharma and Murray point out that de Lisi et al's study highlights an important deficiency in most genetic studies of schizophrenia; they do not examine familial risk of medical, as opposed to psychiatric, disorders.

## Brain Pathology, Neuropsychology and Neurophysiology

There is widespread agreement amongst researchers that there is "a substantial neuropathology in schizophrenia" (Bloom, 1993, p. 224). Both structural and functional evidence of microscopic pathology in the temporal and frontal lobes of the brains of people with schizophrenia are documented, as are changes seen in brain structure and function by the use of noninvasive techniques such as magnetic resonance imaging and PET[1] scans. These techniques have established "the presence of enlarged ventricles, reduced cortical grey matter, and hypometabolism of the frontal lobes and elements of the basal ganglia" (p. 224). Given that such brain changes have been discovered in some people with schizophrenic illness, research is now focusing on which changes are signs of pathology, and on attempts to correlate these changes with symptoms.

In their 1993 review of the literature Royston and Lewis (1993) discuss the latest research into whether the brain abnormalities seen in schizophrenia reflect a static developmental anomaly or whether they result from progressive degenerative pathology, or a mixture of both. The evidence suggests that the abnormalities are developmental rather than degenerative, a finding which leads to a number of new questions and hypotheses. Two recent hypotheses are reported by Royston and Lewis. The first (attributed to Roberts, 1991) is that a genetically determined arrest occurs in brain development in the third trimester of pregnancy. This suggestion would account for some hemispherical imbalance in the abnormal findings, since the development of the left temporal cortex lags behind that of the right. The second hypothesis is one put forward by Stevens (1992) who suggests that schizophrenia may be related to the process of regenerative collateral sprouting of axons, synaptic proliferation and reorganisation which are commonly found after any type of brain damage. Her hypothesis is that anomalous reinnervation might have a role in the pathophysiology of schizophrenia.

The need to further investigate the relationship between clinical symptoms and physical findings such as those found in brain imaging is emphasised by Royston and Lewis (1993). It is known that high levels of ongoing negative symptoms are related to structural abnormalities seen on magnetic resonance imaging and perhaps to frontal lobe deficits (Malmberg & David, 1993). The similarity of the

---

[1] Positron emission tomography

effect of frontal lobe lesions and negative symptoms of schizophrenia is one basis for the suggestion that frontal lobe dysfunction may underlie the negative symptoms of schizophrenia. A study in which twenty men with a diagnosis of chronic schizophrenia underwent PET scanning while free of medication is reported by Wolkin et al (1992). They found evidence of prefrontal hypometabolism associated with severity of negative symptoms, although they suggest that not all negative symptoms may stem directly from prefrontal lobe dysfunction and that not all patients with negative symptoms may exhibit prefrontal dysfunction.

There is also evidence of a link between brain function and auditory hallucinations. Cleghorn et al (1992) set out to study metabolic activity in language areas of the brain using PET scans on twenty two drug free schizophrenic patients. All had experienced hallucinations at some time in the past. During the PET scan twelve of the patients reported auditory hallucinations, ten did not. The researchers conclude that auditory hallucinations involve language regions in the brain in a pattern similar to that of normal subjects listening to their own voices, but different in that hallucinators do not demonstrate activation of left prefrontal regions. The striatum is presumed to play a critical role in auditory hallucinations.

A review of recent research into the neuropsychology and neurophysiology of schizophrenia is presented by Corcoran and Frith (1993). These authors point to an increasing trend toward the study of specific symptoms in schizophrenia and the linking of these to underlying cognitive or neurophysiological deficits. The use of PET studies in this regard is commented on, as is the renewal of research into attentional deficit, in which it is suggested that people with schizophrenia are overloaded with stimuli which reach conscious awareness instead of being filtered out for selective attention.

The research areas discussed to this point are all heavily dependent on understandings of schizophrenia as stemming from a biological base. While many of the leads developed in biological research in psychiatry seem promising, the trend toward biomedicalisation of psychiatry has some harsh critics. Among these are writers like Cohen (1993) who cautions that in this paradigm there is a danger of reductionism to the degree that human social problems are overlooked. He argues that in the extreme biological position social and environmental problems, such as homelessness or unemployment may be framed as individual ones rather than seen as requiring socially constructed solutions such as more inexpensive housing and alternative forms of work. Cohen (1993, p. 519) suggests that new paradigms are needed "to examine the dialectical interpenetration of biological, psychological, and social forces."

Recent biological research findings are not addressed in a considerable proportion of the psychiatric nursing literature. There are several reasons for this, among them the fact that much of the psychiatric nursing literature is theoretical rather than research based. It may be that the biological model is incompatible with the conceptualisation of mental illness in general, or schizophrenia in particular, held by some nurse authors, but more importantly nursing research often concentrates on social concerns rather than on the possible pathology of illness. Commentaries in the nursing literature which do recognise advances in biological psychiatry report them as being either problematic or a source of opportunity for nursing.

It could be that nurses are afraid that recognising the importance of biological factors in illness will mean a loss of the holistic perspective they claim to hold, although the degree to which the holistic perspective is actually adhered to has itself been questioned. McEnany (1991) notes that nurses often talk about psychological problems as distinct from physiological ones in a way which implies that a concept might belong to the mind but not the brain. He says "there is a need for a commitment to a true holism that includes the bio variable in psychiatric nursing's equation of holism" (p. 258). Acknowledging a reluctance among nurses to embrace biological knowledge, Lowery (1992) comments on her frustration that nurses have been happy to adopt concepts from disciplines such as psychology, anthropology and sociology, yet are less keen to use concepts and knowledge generated from the basic sciences.

Accepting the importance of biological knowledge does not obviate the need for attention to the human side of people's problems (Lowery, 1992; Malone, 1990; McEnany, 1991). Indeed it is this attention which characterises nursing (Lowery, 1992). As Liaschenko (1989, p. 155) asserts "biological components function within a social context in which poverty, violence, prejudice, meaning, will, responsibility, tolerance, and caring are among some of the critical and essential features." According to Pothier (1990, p. 77) a new bio/psycho/social synthesis in nursing itself implies two things; the recognition that the goal of psychiatric nursing is the therapeutic use of self, not in a traditional psychotherapeutic sense, but in helping individuals and families live and function better with chronic mental illness, and an opportunity for professional redefinition in which nursing renews the scientific, moral and ethical standards it brings to the mental health system.

If, as Lowery (1992) suggests, psychiatric nursing more than any other professional group will be challenged to change its thinking, practice, research and education as a result of biomedical discoveries, then there is reason for both the apprehension and the excitement reflected in the literature. Indeed there are suggestions (McBride, 1990; Lowery, 1992) that an increasingly medicalised psychiatric profession will actually lead to increased opportunities for development of the nursing role: that ongoing commitment to care, comfort and well being of another which is the moral underpinning of nursing practice (Liaschenko, 1989). This view is supported by McKeon (1990, p. 19) who foresees that "as psychiatry realigns with medicine and advances in treating diseases of the brain, nursing practice can be distinguished and differentiated by the demonstrated ability to care." Thus the incorporation of findings from biological research into the care of those with mental illness may well have the effect of strengthening the holistic focus of nursing, accentuating the similarities between mental and physical illness and changing the theoretical underpinnings of psychiatric nursing practice.

There was a time when schizophrenia and other psychoses were believed to be caused by "interpersonal traumas" but the new dominant paradigm is a biomedical one (Malone, 1990, p. 4). While nursing must acknowledge scientific developments in the biomedical arena, the focus of nursing remains with people's human needs and their experiences of illness:

> Pervasive clinical "failures" using psychotherapy, the dramatic effect of neuroleptics on the course of mental illness, and increasing technical sophistication have fuelled a revolution that asserts the biomedical model as the dominant paradigm in the treatment of severe and persistent mental illnesses. Irrespective of these biomedical advances, human needs and responses are the purview of nursing.
>
> (Malone, 1990, p. 4)

It is the human experience of schizophrenic illness over and above its physical causes and effects which this present study set out to investigate.

## TREATMENT

Both biological and non-biological approaches to the treatment of schizophrenia are documented in the literature. In most cases antipsychotic drugs are the first line of treatment, but drug therapy may be supplemented with some form of psychosocial intervention with individuals or groups, including education or training programmes for those with the illness and, in some cases, their families. There is widespread agreement that early identification and intervention - pharmacological and psychosocial - lead to the best outcome (Birchwood, Macmillan & Smith, 1992; Lieberman & Sobel, 1993).

### Drug therapy

The efficacy of the antipsychotic group of drugs in controlling or reducing symptoms such as hallucinations, delusions and thought disorder has been clearly established since their discovery forty years ago (Kissling, 1992). It is believed that these drugs, which belong to several different classes (eg. phenothiazines, thioxanthenes, butyrophenones) exert their antipsychotic effect through blockade of central dopamine receptors in the brain, and that their neurological toxicity is also due to this effect (Seeman, 1985; Wirshing & Marder, 1993). The group of drugs is effective in achieving control of positive symptoms which are hypothesised to be due to dopamine overactivity. Excepting the newer atypical drugs clozapine and respiridone, which will be discussed later, the group does not act beneficially on negative symptoms and as a consequence these symptoms are postulated to be caused by a different brain mechanism (Seeman, 1985).

Virtually all of the antipsychotic drugs produce unpleasant side effects. Anticholinergic effects[2] include dry mouth, constipation, blurred vision, cardiovascular effects including tachycardia[3] and syncope,[4] and urinary hesitancy

---

[2] Anticholinergic effects are those resulting from the blocking of impulses through the parasympathetic nerves.

[3] Tachycardia - an abnormally rapid heartbeat.

[4] Syncope - fainting.

or retention. Endocrine side effects include galactorrhoea,[5] menstrual disturbances and impaired sexual functioning. Central nervous system side effects include both sedation and extrapyramidal side effects such as dystonias, akasthisia and parkinsonism.[6] Skin sensitivity, with a greatly heightened risk of sunburn is common to most people taking antipsychotic medication. The most severe reactions are tardive dyskinesia, an often irreversible series of involuntary movements frequently involving the face and mouth, and the rare but potentially fatal neuroleptic malignant syndrome in which the patient develops rigidity, fever, tachycardia, tachypnoea,[7] blood pressure changes and alterations in mental state ranging from confusion to coma. The dose of the particular drug and its potency both affect the occurrence and severity of side effects (Wirshing & Marder, 1993; Yudofsky, Hales & Ferguson, 1991).

In their review of recent research into drug treatment in schizophrenia, Wirshing and Marder (1993) comment on efforts toward increased understanding of the neurochemical mechanisms involved in side effects (particularly extrapyramidal reactions) of neuroleptics, and the continued search for new antipsychotic drugs. Three relatively new drugs are now available in some areas and for some patients, and research into their effectiveness, side effects and action is now evidenced in the literature. Clozapine, an atypical antipsychotic drug with a different side effect profile from the main group of antipsychotics was first discovered some twenty five years ago. It has been used in Scandanavia for some time, but was not in use in the United States until 1990 (Yudofsky, Hales & Ferguson, 1991). It has recently begun to be used in New Zealand but is very expensive, and may only be prescribed to a very limited group of "treatment resistant" patients who must undergo weekly blood monitoring. The reason for the conditions, which have been imposed by the company which manufactures the drug, is that it carries a relatively high (1 to 2 per cent) risk of

---

[5] Galactorrhoea - secretion of milk unconnected with nursing an infant.

[6] Extrapyramidal side effects involve abnormal involuntary movements, alterations in muscle tone (dystonia) and disturbances in posture. Akasthisia is a term used to describe motor restlessness and anxiety. Parkinsonism refers to a disorder which mimics the symptoms of Parkinson's disease, including muscle rigidity, mask-like expression, tremors in resting muscles, weakness and a characteristic gait.

[7] Tachypnoea - very rapid, usually shallow, respirations.

agranulocytosis.[8] Other side effects include an increased rate of seizures, tachycardia, lowered blood pressure and excessive salivation.

Clozapine is of particular interest because of its effectiveness in a significant number of patients who have not been helped with other antipsychotic medication (of the order of 30%), because it carries a considerably lower risk of movement disorders and because it does not appear to cause tardive dyskinesia (Clozapine Study Group, 1993; Yudofsky, Hales & Ferguson, 1991). The drug is considered of major significance because it has been found to be superior to haloperidol for treating positive symptoms (Breier et al, 1994; Lieberman et al, 1994) while also exhibiting some effect on the negative symptoms of schizophrenia (Clozapine Study Group, 1993; Breier et al, 1994; Lieberman et al, 1994; Wirshing & Marder, 1993). The efficacy of the drug, its atypical action, which has implications for the understanding the pathophysiology of treatment-refractory schizophrenia, and its lower incidence of extrapyramidal side effects have lead some researchers to suggest that clozapine is "the most significant development in antipsychotic drug pharmacology since the advent of chlorpromazine" (Lieberman et al, 1994, p. 1744).

Two other new drugs are documented in the research literature though not yet generally available. Respiridone, like clozapine, provides some help with negative as well as positive symptoms, and has a greatly reduced rate of extrapyramidal side effects. Remoxipride is thought to have an antipsychotic activity comparable to that of the older neuroleptics, but it, too, causes fewer extrapyramidal symptoms and less mental dulling. As a relatively non-sedating, well tolerated drug remoxipride may well replace the conventional low potency drugs such as thioridazine and chlorpromazine (Wirshing & Marder, 1993).

Because of the effectiveness of neuroleptic medication, which controls but does not cure schizophrenia, it is important that patients continue to take medication for some time. Kissling (1992) suggests that half of all schizophrenic patients relapse within one year of their last episode and attributes this to a lack of basic pharmacotherapy. In Kissling's view it is not helpful to blame the patient or the illness, but rather to recognise that clinicians are not agreed on any of the details involved in prescribing such medication, each psychiatrist advising his or her

---

[8] Agranulocytosis - a condition in which there is a sudden drop in the body's production of leucocytes (white blood cells), leaving the body defenceless against bacterial infection.

patients differently as to indications, duration of treatment, lowest advisable dose level and so on. In addition, the risk of relapse cannot be predicted with any certainty (Kissling, 1992, p. 135). In his paper Kissling reports on a consensus conference in Bruges which was the first international convention to adopt detailed guidelines for the prevention of psychotic relapse in patients with schizophrenia. Among the agreed guidelines is the need to involve the patient significantly in consultation about the risks of medication and weighing up the risks of side effects, especially tardive dyskinesia. Kissling suggests that if the guidelines were adopted relapse rates might be halved.

## Psychosocial interventions

While the positive symptoms of schizophrenia may be ameliorated and controlled by antipsychotic medication, negative symptoms are less responsive to medication. Psychosocial interventions show considerable promise in helping people deal with negative symptoms (Hogg & Hall, 1992). Hirsch and Bristow (1993) reviewed recent research on non-biological interventions in schizophrenia. They remark on the paucity of research into these types of treatment in comparison to pharmacological studies, and report that of the non-biological factors involved in the treatment of the illness, cognitive-behavioural therapies and treatment for patients living in families with high expressed emotion (EE) are the best researched.

Family therapy is a domain outside the scope of this study, but some aspects of the discussion regarding expressed emotion are worthy of mention, particularly since the nursing literature is reflecting these interventions and because the research reports contain conflicting results. In broad terms the EE hypothesis suggests that a patient who lives in a family where there is high expressed emotion, judged by criticism, over involvement and hostility toward the patient, is more likely to relapse than one who lives in a low EE family. Controversy in the literature centres on findings: whether in fact high EE predicts relapse; and on the meaning of the expressed emotion. Some researchers suggest that high EE may be a reaction to a disturbed family member rather than its cause (Hirsch & Bristow, 1993). Fairly general agreement exists as to the usefulness of psychoeducational work with families, but at this stage the mechanisms involved and ideal treatment programmes are not generally agreed upon.

Vaccaro and Roberts (1992) review literature relating to the use of educational programmes in which people with schizophrenia are taught social and coping skills, concluding that a wide variety of skills, both practical and interpersonal, can be learned in specific training situations. They emphasise that for maximum effectiveness interventions for people with schizophrenia need to be envisaged as being long term, and provide for functional as well as symptomatic assessment.

> Biomedical and psychosocial interventions must be embedded in systems of care which presume that care for schizophrenic individuals must be long term or life long, and comprehensive and continuous in character. ... The most effective psychosocial treatment - whether provided in individual, group or family therapy, inpatient ward or community program - contains elements of practicality, problem-solving of everyday challenges, socialisation and vocational activities, and specific goal orientation. A supportive and positive therapeutic relationship is central, and should infuse all treatment contacts.
>
> (Vaccaro & Roberts, 1992, p. 112)

Supportive attitudes and good alliances with therapists are also recommended by researchers who have studied the use of psychotherapy with schizophrenic patients. Zahniser, Coursey and Hershberger (1991) note that while research into the efficacy of individual psychotherapy for those with schizophrenia is discouraging, both clinicians and consumers believe it to be an important part of treatment. These researchers surveyed therapists, from a variety of professional backgrounds, working in a large suburban mental health system in Maryland. The therapists were asked about the types of interventions most often used with schizophrenic clients, the most important issues which arose, and the problems which impeded therapeutic work.

Forty two of the seventy five therapists surveyed were working with outpatients who had a schizophrenic illness. These respondents indicated that 59 per cent of their time was spent in supportive, problem solving work, only 32 per cent in traditional psychotherapeutic work. The issues identified by the therapists as most important were relationships, family concerns, losses due to mental illness, and the role of medication in the life of the client. Next in importance were dependency, depression and the client's feelings of loss of control over his or her life. The most significant impediments were a lack of community resources, clients' non-compliance with medication, lack of motivation and "related or dual diagnoses" (p. 908). It is not clear whether the latter problem actually refers to alcohol and drug abuse or to other problems such as intellectual disability.

The researchers observe that there is a mismatch between the supportive, problem solving, pragmatic concerns which took up most of the therapists' time and the general human concerns and those related to chronic disability which were also seen as important. The question is raised as to whether the clients would agree with the perspective presented by the therapists. A reference is made to an unpublished study (Coursey, Keller & Farrell, 1990) which suggests that in fact clients each have a large number of significant therapeutic issues. It is suggested that there is a need for a type of psychotherapeutic intervention designed specifically for people with schizophrenia.

> The assumption that traditional forms of psychotherapy, developed for neurotic patients, should provide an adequate therapeutic framework for schizophrenic patients may well have been a blind alley. It may be time to stop our procrustean efforts and begin designing interventions specifically for people with schizophrenia.
>
> (Zahniser, Coursey & Hershberger, 1991, p. 911)

In light of research findings which suggest the need for good therapeutic alliances between professionals and clients, along with the growing recognition that professionals have much to learn from clients' descriptions of their experiences and identification of their own needs, it may well be that the kind of interventions suggested by Zahniser et al (1991) will develop from professionals' active engagement with those they aim to help. Strauss (1989, p. 179) emphasises the ability of those who have experienced a schizophrenic illness to enlighten clinicians and researchers, suggesting that "to understand, study, and treat severe psychopathology more effectively it is crucial to focus on the interaction between the person and the disorder over time" and that this means listening to what "patients are trying to tell us about their subjective experiences that we systematically fail to hear."

### Effectiveness and cost of psychosocial intervention

Two criticisms sometimes made of the movement toward community care are that it is more costly than hospital based treatment and that in many places funds have not moved into the community along with the patients. Stein (1987) reports on an experimental programme conducted fifteen years previously in Wisconsin, and on the results of four similar studies, three conducted in the United States and one in Sydney, Australia. From the rationale that many people with schizophrenia suffer long-term impairments which seriously interfere with their ability to organise and maintain a stable adjustment in the community, the experimental programme involved a group of people with schizophrenia being cared for by rostered professionals who taught budgeting skills, helped with financial management, intervened in financial emergencies, gave depot medication,[9] assessed patients every day and visited anyone whose wellbeing the staff were not sure about.

A control group received traditional treatment, short term hospitalisation, and appointments at the mental health clinic for assessment, medication, social activities and some therapy. The patients in the control group were left to keep their own appointments; if they did not do so they were not followed up. Stein (1987) reports striking results which were similar in each of the studies. Hospitalisation rates dropped dramatically from the previous revolving-door pattern in the experimental groups. Clinical indicators such as symptoms, employment rates, social relationships and life satisfaction measures also showed significantly greater improvement in the experimental group. In all of the studies the experimental programme was demonstrated to cost approximately one quarter of that for long term institutional care and approximately the same or a little less than traditional revolving-door systems.

Although the efficacy of many forms of psychosocial intervention is supported by research, Bentall (1990, pp. 294-295) comments on the widespread and in his view, unjustified, pessimism about their usefulness amongst clinicians. Bentall suggests that the biggest problem with these interventions is that they are seldom implemented, and he places the blame for this on the dominance of biological psychiatry in mental health services. Whether this argument is realistic or not is

---

[9] Depot medication is given by injection in a form which is only slowly absorbed by the body, thus enabling longer intervals between doses than is possible with more rapidly absorbed forms of the drug.

difficult to determine. It does seem to continue the ideological argument over which is the better form of assistance, rather than allowing for an inclusive position in which a variety of forms of intervention are considered ideal in helping people to overcome the effects of an acute illness and to live with the ongoing limitations which remain after resolution of an acute episode.

## PSYCHIATRIC NURSING AND THE PERSON WITH SCHIZOPHRENIA

In New Zealand, as in many other countries, nurses are the professional group in most frequent contact with the seriously mentally ill in the community, and adhere to models which are wider in scope than the traditional biomedical or psychological models.

At the forefront of theory development for psychiatric nursing practice is the work of Hildegard Peplau. Peplau's first major work was published in 1952, more recent work appearing as late as 1992. Widely acknowledged as having had a major influence on psychiatric and on general nursing, Peplau is also credited as having had a large role to play in nursing's development as a profession separate from medicine (O'Toole & Welt, 1989). Peplau's interpersonal theory of nursing is based largely on the psychoanalytic work of Harry Stack Sullivan, and focuses on the interpersonal relationship between nurse and patient. Underlying the premises of Peplau's theory is the assumption that mental illness involves unconscious emotional experiences, often stemming from early childhood, and that people can learn to overcome ineffective behavioural patterns in order to become more fully themselves.

In Peplau's view the work required of a nurse in communicating with psychiatric patients demands "considerable self-discipline" (1989, p. 276) in that it is not the customary social mode of talking. The nurse must learn to relate with patients in a therapeutic and professional way and it is the nurse who makes assessments and decisions regarding the patient's "real" problems. This is necessary because "psychiatric patients are lacking in the intellectual and interpersonal competencies so necessary for the work involved in their search for understanding" (p. 275).

Peplau's work on interpersonal theory has had, and continues to have, an important impact on the theoretical understandings of psychiatric nurses in New Zealand. It is also arguably the most commonly used theoretical nursing framework in psychiatric settings in the USA and Canada, closely followed by that of Orlando (Hoffman & Bertus, 1992). As these latter authors note, most recent psychiatric nursing/mental health text books contain an explanation of a broad range of theories from the psychological and behavioural sciences, and some now also include reference to the work of other nurse theorists in addition to Peplau (eg. Orem, Roy, King and Rogers). Brief attention is paid to Leininger's and Watson's work on caring in Rawlins, Williams and Beck (1993), and Wilson and Kneisl (1988) refer to Benner's ideas as central to their section on philosophical perspectives in nursing theory. Thus in the American literature there is evidence of widening theoretical perspectives on psychiatric nursing.

Meanwhile other modes of psychodynamic theory are also evident in the literature, for example that based on an object-relations framework (eg. Kerr, 1990; Sayre, 1990). The psychodynamic approaches in nursing practice each in some way imply an unequal relationship between nurse and patient. The nurse is in touch with reality and both able and required to interpret patients' speech and actions in order to help them overcome early psychic damage and therefore to mature. While nursing interactions are dependent on trust, the base from which this is derived is not one of two equal human beings. The distance which such a stance requires of nurses can, however, no longer be taken as unequivocal and is argued against by recent researchers and theorists. As Burnard (1989, p. 71) states "surely, it is safer that we accept what people tell us about themselves. Surely, at least, the psychiatric nursing relationship must be based on trust, acceptance and empathy, not on interpretation, 'hidden meanings' and 'reading between the lines'."

The centrality of a caring, committed, involved stance in nursing the mentally ill is also echoed by Watson (1991). He undertook a phenomenological study with six inpatients in an acute ward in a New Zealand psychiatric hospital. Watson does not give the diagnoses of the patients he interviewed, but reports that they all felt that a caring attitude and behaviours by the nurses helped them to cope with their illness. Watson (p. 13) comments on this finding as challenging "some of our formal and informal ideology about maintaining distance from patients," historically a value in nursing. The potential difficulties inherent in changing nursing's focus toward therapies which facilitate "a respectful, caring, health-oriented, and active focus," those found to be most consistent with nursing's metaparadigm, are acknowledged by Montgomery and Webster (1993). These authors (p. 8) warn that, because of the prevalence of the psychodynamic model "natural feelings of compassion may be devalued and viewed with suspicion in psychiatric settings; and labelled as countertransference,[10] emotionality, or codependency.[11]"

There is a difference between an attitude of care and respect and one in which no hope is held for clients' abilities to change their situations. In reporting a recent ethnographic study of an acute psychiatric ward of a general hospital in New Zealand, Boddy (1992) points out the problems which arise when these two attitudes are confused. Boddy describes the particular ward she studied as fulfilling a function in dealing with outpatients living in the community as well as those admitted for care. Telephone calls from outpatients took up a considerable amount of the time of nurses on the ward, as did "drop in" visits by outpatients. The culture of the ward is described as one in which "caring by nurses was most often observed to be expressed as nurturance and acceptance of patients' needs for a safe haven from the outside world at times of stress" (Boddy, 1992, p. 189). While these attitudes could be seen as meeting some of the requirements for empathetic relationship, Boddy also notes that the nurses did not harbour hope for change in the majority of patients, and often failed to help them learn new skills, change behaviours or manage their lives independently in the community. Boddy questions whether the nurses' attitudes themselves exacerbated the high readmission rate. "In this context the high readmission rate was seen as a consequence of fluctuations in the illness, rather than as an outcome of care. Because dependency was seen as inevitable, accessibility of the service to patients was a primary value." (Boddy, 1992, p. 191)

A rather different perspective on rehospitalisation is presented by Fetter and Lowery (1992) who investigated staff and patient perspectives of rehospitalisation in those with severe mental illness. A convenience sample of 120 rehospitalised schizophrenic patients and 162 inpatient unit staff (one half

---

[10] Countertransference is the unconscious process by which a therapist projects feelings from another relationship onto current interactions with a client.

[11] Codependency is a poorly defined term derived from the addictions field. It is used to describe habitual, self-defeating behaviours which diminish people's capacity for open honest relationships. Sometimes codependents are also "enablers" who help others to remain unwell or addicted rather than risk confrontation and change.

nurses, the other a mixture of professional groups) were involved in the study. Both staff and patients were asked about reasons for rehospitalisation; patients about their own readmission and what had caused it, and staff about readmitted schizophrenic patients in general. While both groups tended to cite internal causes for readmission, patients were more likely to focus on the illness and staff on aspects of the effort made or not made by patients, especially noncompliance with medication. The researchers note that up to 50 per cent of people suffering from schizophrenic illness relapse while adhering to their prescribed medication regime. In these cases, it is suggested, it may be that it is, as the patients indicated, a function of their illness which has lead to their relapse. If this is so, encouraging attribution related to effort may have negative rather than positive outcomes, with patients blamed for their illness rather than acknowledged as acting in their own best interests in seeking help.

There is considerable attention paid in the nursing literature to the concept of expressed emotion and to interventions which take this concept into account in working with the families of those with schizophrenia. In a discussion and review paper Simpson (1989) asks whether nurses' expressed emotion might be a variable related to the outcome of those with schizophrenia. Those advocating the EE approach suggest that the environment which is related to best patient outcomes is one which is low in expressed emotion; accepting, tolerant and sympathetic toward the patient. Simpson (p. 464) notes that his own clinical experience with a long-stay therapeutic community of schizophrenic patients is of an environment which resembles a low EE approach, and is in stark contrast with the kind of "bruising affair" which is confrontation in a drug dependency unit. His argument that more research is needed to clarify the effect of nursing styles of relationship and encounter is interesting in light of the apparent trend toward supportive therapy and long term relationships between nurses and their clients who suffer from schizophrenia.

## CHANGES IN THE HEALTH CARE SYSTEM

International trends toward decentralisation, deinstitutionalisation and community care have impacted on the settings in which nurses meet clients and on the kinds of interactions and interventions which are possible and necessary. In New Zealand many people with schizophrenia have regular contact with a psychiatric district nurse in the community. Others are followed up through outpatient hospital visits or by their general practitioner. No published research was found relating to the work of psychiatric community nursing in New Zealand, but much of the international literature is applicable to nursing in this country.

Hawthorne (1993) undertook a small scale grounded theory study in which she interviewed community psychiatric nurses in Victoria, Australia, about their work with long-term community clients. This research demonstrated that the nurses worked in a different model of therapy from that advocated by much of the psychosocial literature. They were much more concerned with developing a person-centred therapeutic relationship than with a problem-centred approach and symptom management. Their focus was not overtly concerned with change and so matched neither a problem oriented nor a psychodynamic model. These nurses described the importance of assisting clients in solving practical problems (an example given is taking the cat to the vet); of listening actively, even to delusional ideas; of validating the client's feelings, and of a considerable degree of self disclosure on their part. Close relationships with clients were held to be of primary importance and Hawthorne suggests that longstanding, consistent relationships which are not problem oriented may be valuable with this population. She comments on the foundation of some of the nurses' skills in Carl Rogers' work, and on the difference between the working methods used by the nurses and the textbook descriptions of therapeutic interventions found in many psychiatric nursing textbooks. It would appear that more research is needed into the effective strategies used by nurses in the community. Hawthorne's finding that nurses placed a strong emphasis on longstanding relationships parallels findings by Sladden (1979) and Pollock (1989) who both studied the work of community psychiatric nurses in Scotland.

The move toward closure of psychiatric hospitals and the care of the mentally ill in the community has had a number of repercussions for nursing. One of these is the requirement for nurses to practice in settings for which most have not been trained and with which they are not familiar, including group homes, jails, streets and shelters for the homeless (Aiken, 1987; Chafetz, 1990). Further, the needs exhibited by clients in some of these settings extend into areas of physical care and social assistance which have not previously been a large part of the role of psychiatric nurses. Aiken suggests that the public health nurse model is close to that now needed in the community by many seriously mentally ill clients yet this is a role declining rapidly under New Zealand's health care reforms, and one which has not (formally at least) traditionally encompassed psychiatric care.

Chafetz (1990) presents a compelling argument about the dangers of mutual withdrawal between nurses and clients when the latter are homeless and present with a magnitude of problems. Even knowing where to start may be difficult, especially for health care professionals educated in a model of a hierarchy of needs. In these situations conceptualising clients' problems as physiological leaves the potential for nursing to turn away from the "social concomitants of disability" (p. 451). While homelessness among the chronically mentally ill is not a documented problem in New Zealand, the potential for withdrawal by nurses and anger, resentment and frustration amongst clients still exists. Clinicians in community nursing frequently visit clients in living conditions which are frankly shocking to the nurses, psychiatric nursing being no exception. Meanwhile recent Government-initiated changes in funding for social services, including voluntary agencies to whom nurses might have turned for client assistance, means that many of the latter are stretched to the limit. Creative solutions are not always easily found in these circumstances and several recent cases have eventually been brought to media attention before they have been resolved.

Writing of the complex relationships between chronic mental illness and sufferers' abilities to take care of themselves, Connelly and Dilonardo (1993) point out that many people with severe mental illness struggle with residual thought disturbance, problems with memory or concentration and the negative symptoms of schizophrenia. In addition, community living means facing the stigma of illness and the prejudice of others; socioeconomic problems such as minimal income and housing problems; and a cost-benefit struggle with medications which often induce unpleasant side effects. The authors recommend that nurses support client autonomy and negotiate with clients the best ways for them to care for themselves. They emphasise that the quality of the relationship between nurse and client is central to effective care in this complex context.

Recognition that some people with mental illness will periodically become ill and need further professional assistance is advocated by Beebe (1990). She argues that by reframing their outlook on recidivism as appropriate help-seeking behaviour rather than a failure to cope, nurses have the potential to improve the self-concept of their clients who may then see their efforts at self-help as successes rather than as failures. While Beebe does not make the link in her paper, such an attitude is in line with that commonly shown toward those with chronic physical illness or disability, and is congruent with the premise that the chronically mentally ill have a lifelong illness which will include exacerbations and remissions (Bryson, Naqvi, Callahan & Fontenot, 1990). The stress-vulnerability model of schizophrenia described in Chapter One is also congruent with this attitude.

The view that some people with mental illness face a prolonged period dealing with the ramifications of illness is also held by Rawnsley (1991) who evaluates the Corbin and Strauss trajectory model of chronic illness in relation to mental illness. Rawnsley concludes that the trajectory model is highly applicable to chronic mental as well as physical illness, suggesting that those with chronic mental illness are actually situated on a timeless trajectory.

> Chronic mental illness is an existential predicament, a way of being at odds in the world. Afflicted persons have described their life as "a living Hell." And just as in dramatic portrayals of that theological construct of eternal hopelessness, time seems suspended for those who struggle through decades with major mental illness. It is hardly hyperbole then, to characterise the chronicity of major mental disorders as a "timeless" trajectory, seemingly without purpose, without progress, without resolution and without end.
>
> (Rawnsley, 1991, pp. 209-210)

The original trajectory model provides for collaborative planning and monitoring of symptom control, which Rawnsley sees as appropriate for chronically mentally ill clients and interdisciplinary team members, although she also recommends that more research is needed into the experiences of those who suffer from mental illness, in order that disciplinary assumptions about others' experience be validated or overturned. While she maintains that psychiatric nursing centres on the therapeutic use of self, the position taken by Rawnsley is not one of professional distance, but rather involves the need to attempt to understand the world in which the mentally ill person dwells. "Only through the richness of data generated from the realities of the lived experience of mental illness can the biases that now occlude professional vision be disclosed"

(Rawnsley, 1991, p. 211). It was in order to collect and analyse data from just such a perspective that this study was conducted.

## THE EXPERIENCE OF SCHIZOPHRENIA

The focus of this study is the subjective experience of schizophrenic illness as reported by people who have the illness, are relatively well and are living in the community. Little evidence of similar studies was found in the literature. While clinicians from all disciplines have relied on the subjective reports of their clients, including those who are acutely unwell, research which takes note of the patient's perspective has been relatively uncommon until very recently. Of the studies which are available, the majority are concerned with the psychotic experience, and many deal with specific symptoms or groups of symptoms. A few studies have examined experiences of people with schizophrenia in the community rather than in hospital, taking a broader perspective on that experience. A number of autobiographical accounts are also to be found in the scientific and popular literature, documenting the authors' own experiences of schizophrenic illness.

### Fictional and autobiographical accounts of illness

There are few public accounts by people with schizophrenia about how the illness has affected them (Deveson, 1992). Deveson postulates that one reason for the dearth of such material is that until recent improvements in management those affected by the illness were neither strong nor coherent enough to write about what had happened to them.

> Another reason is that the experience of madness is invalidated in our culture. Because we do not understand it, we fear it. We try to distance ourselves by uneasy humour, or by overt rejection. We no longer lock people up but neither do we want them living in our street. The stigma has been so great that mental illness has been silent and silenced.
>
> (Deveson, 1992, p. 10)

First person accounts, whether written or oral, are, however, the most direct means by which clinicians and researchers can begin to understand what this illness experience is like, and from which to begin to establish a base for ongoing communication with those affected by it. Although it is not particularly easy to locate, such a literature does exist. The journal "Schizophrenia Bulletin" runs a regular "First Person Account" column and some researchers have collated references to autobiographies (eg. Sommer & Osmond, 1983).

Most written accounts of schizophrenic illness deal primarily with the experience of acute psychosis and hospitalisation. This is not surprising, given the powerful nature of the psychotic experience and its effect in profoundly altering thoughts. Some accounts communicate excitement and intrigue, others fear in the face of the psychotic experience. Much of this literature contains expressions of loneliness, isolation and a feeling that the humanness of those with mental illness is not recognised.

Some powerful and disturbing examples are given in Janet Frame's (1961) work "Faces in the Water." While this book is a novel, it is known that Frame did spend time in a psychiatric hospital, an experience from which it can be presumed that some of her material is drawn. Frame writes of the terror felt by people undergoing unmodified ECT[12] and of the interpretation of this as punishment and as a warning that emotions are to be kept to oneself:

> Every morning I woke in dread, waiting for the day nurse to go on her rounds and announce from the list of names in her hand whether or not I was for shock treatment, the new and fashionable means of quieting people and of making them realise that orders are to be obeyed and floors are to be polished without anyone protesting and faces are to be fixed into smiles and weeping is a crime. Waiting in the early morning, in the black-capped frosted hours, was like waiting for the pronouncement of a death sentence.
>
> (Frame, 1961, p. 16)

---

[12] Electric shock treatment without concomitant use of anaesthetic and muscle relaxant, both routinely used today.

Frame is also acutely aware of both the way in which mental illness is feared amongst those who do not understand it and the need of those who are ill for kindness and human warmth.

> There is an aspect of madness which is seldom mentioned in fiction because it would damage the romantic popular idea of the insane as a person whose speech appeals as immediately poetic; but it is seldom the easy Opheliana recited like the pages of a seed catalogue or the outpourings of Crazy Janes who provide, in fiction, an outlet for poetic abandon. Few of the people who roamed the dayroom would have qualified as acceptable heroines, in popular taste; few were charmingly uninhibited eccentrics. The mass provoked mostly irritation hostility and impatience. Their behaviour affronted, caused uneasiness; they wept and moaned; they quarrelled and complained. They were a nuisance and were treated as such. It was forgotten that they too possessed a prized humanity which needed care and love, that a tiny poetic essence could be distilled from their overflowing squalid truth.
>
> (Frame, 1961, p. 98)

While Frame's work is now 30 years old and we may now not hear "the sort of near-abuse that one hears spoken every day by mental nurses to their patients" (p. 124), presumably those who were in psychiatric hospitals at that time still wear some scars. There is evidence in other writing that staff in psychiatric hospitals may still not be providing the warmth, support and care which patients would like. Folkard's (1992) autobiographical work contains such evidence. She writes of the effects of medication on her body and of her anger at not having been informed of what was happening to her:

> Most mornings I found I was fuzzy from what I later learnt was low blood pressure. I had to walk my way along the walls to the bathroom being careful not to fall. I was never told that this unsteadiness might have been caused by the drugs I was given.
>
> At times I felt a toxicity of body just like with any other illness - the effects of the drugs seemed to make me feel lifeless and dumb. This is the saddest side that I have found to the

> treatment of the mentally sick. So often you are treated as mindless bodies. This feeling brought anguish and an animal-like sense of survival to me.
>
> (Folkard, 1992, pp. 24-25)

In the extracts quoted both Frame and Folkard eloquently express their feelings of distance from others and from the understanding of those who might help them. Others writing of acute episodes of psychosis have been concerned with different things. Kaplan (1964) for example, refers to the work of Anton Boisen, who writes of his religious awakening and the development of a serious attitude toward life as a result of his mental illness.

Once an acute episode is resolved many challenges remain. Macdonald (1964) describes fighting depression, loneliness and ideas of suicide or of returning to the safety of hospital even though she knew that the latter would cost her in terms of self confidence and self reliance. She describes the difficulty she faced in learning to make new friends and of recognising when she should not trust others. In addition she writes of the precarious balance she needed to find between work, hobbies, boredom and change, and her need to sleep and eat well and to avoid excessive noise. The threat of a relapse was always present:

> Living with schizophrenia can be living in hell, because it sets one so far apart from the trend of life followed by the majority of persons today, but seen from another angle it can be really living, for it seems to thrive on art and education, it seems to lead to a deeper understanding of people and liking for people, and it's an exacting life, like being an explorer in a territory where no one else has ever been. I am often glad that illness caused my mind to "awaken" 11 years ago, but there are other times when I almost wish that it would go back to sleep. For it is a constant threat. A breakdown in physical health, too much pressure, too many responsibilities taken on because they sound interesting to the "well" side of me, and I could be plunged back into the valley.
>
> (Macdonald, 1964, p. 184)

The effect of schizophrenic illness on the whole of a person's sense of self is described by Ruocchio (1991) who reports being afraid of her own brain:

> My greatest fear is this brain of mine, which torments me in times of psychosis, always threatens me, and seems always to be laughing at me, scorning my vulnerability. The worst thing imaginable is to be terrified of one's own mind, the very matter that controls all that we are and all that we do and feel.
>
> (Ruocchio, 1991, p. 357)

More pragmatic concerns relating to a need to find housing and meaningful activity and to face up to the sometimes unrealistic expectations of others (eg. Peterson, 1982) or to deal with interpersonal stresses at work (Anonymous, 1989) are also documented in the literature. Lovejoy (1982) emphasises the importance of hope and describes the negative expectations of others as amongst the greatest obstacles to recovery:

> My experiences, as well as the experiences of others from the halfway house, have taught me that regardless of the cause(s) of mental illness, progress toward recovery cannot occur when there is no hope. Negative expectations and stereotyping are among the greatest obstacles to recovery, and keep many mentally ill persons immobilised by defeat and despair.
>
> (Lovejoy, 1982, p. 608)

It is clear from the accounts of those who have written of their experiences that people who have suffered a schizophrenic illness have much they want to communicate and, by doing so, have much to offer in increasing the understanding of health professionals. Over the past three decades a few research studies have been conducted in an endeavour to better understand the subjective experience of schizophrenia or of some symptoms associated with the illness. As has previously been stated, most of these studies have been concerned with the experience of psychotic illness, but some have focused on people's experience after the resolution of an acute episode of illness.

## The experience of psychotic illness

In one of the earliest studies of the subjective experience of schizophrenia, 26 newly hospitalised patients were asked to describe recent changes in their experience (McGhie & Chapman, 1961). Patients reported increased visual and auditory vividness, changes in bodily awareness, a loss of spontaneity and increased need to plan every action step by step. The researchers hypothesise that the illness is characterised by "a decrease in the selective and inhibitory functions of attention" (p. 114). This primary disorder leads to a number of other changes. They include a change in perception toward a more global, undifferentiated state; a merging of sensory channels, which McGhie and Chapman likened to the phenomenon of synaesthesia,[13] disturbances in control of willed action, especially a heightened awareness of bodily functions and impulses which are usually outside conscious awareness; and a decrease in concentration and development of thought disorder, related to a flooding of information and an inability to organise this in a logical sequence. McGhie and Chapman (1961) commented that an examination of schizophrenia in a group of patients who have had the disorder for some time would be profitable but they felt that the primary disorder would be obscured by secondary reactions and a general deterioration in these people, and that they would be both inaccessible and unreliable as experimental subjects. Today the evidence from autobiographical accounts of illness and from studies which have focused on such participant groups points to the fact that people who have lived with a schizophrenic illness for many years are indeed well able to relate their experience.

Freedman and Chapman (1973) criticise McGhie and Chapman's (1961) study on two grounds; the lack of a clear interview schedule and the absence of a control group. The former researchers used autobiographical articles and books by people who had experienced a schizophrenic illness from which to construct an interview schedule. They then interviewed a sample of 20 schizophrenic patients and twenty patients with another diagnosis on their first day of admission to a psychiatric ward or mental health clinic. Each was interviewed prior to taking any medication. These researchers found that approximately half of those with schizophrenia reported a pattern of attentional deficit similar to that postulated by McGhie and Chapman (1961). Other problems which were experienced by those

---

[13] The production of one kind of sensory experience after the stimulation of another sense. People who experience this phenomenon may "smell" colour or "taste" shapes etc.

with schizophrenia were thoughts which interrupt speech; visual misperception of objects; difficulty making sense of speech and misidentification of people.

A symptom specific approach to the study of schizophrenia has been taken by several researchers. There are particular difficulties in such an approach because the symptoms of schizophrenia are variable and thus not all found in everyone who has the illness, and because some symptoms are shared across a range of diagnostic categories. Hallucinations, for example, are not experienced by all people with schizophrenia, while they are experienced by people with other psychiatric illness (and under certain circumstances by people who are not mentally ill). This is one of the reasons for some of the latest criticisms of schizophrenia as a concept (eg. Boyle, 1990). However, findings from research in which a particular symptom has been studied often tend to suggest that people with different diagnoses react differently to the symptom and are therefore more likely to respond to different approaches in treatment.

An unusual study to test the similarity of accounts of hallucinations by people with schizophrenia, those taking hallucinogenic drugs, and people who had experienced mystical experience such as communication with God, was carried out by Oxman, Rosenberg, Schnurr, Tucker, and Gala (1988). Using textual analysis they examined autobiographical accounts by people in each of these groups, matching them with a control sample of autobiographical writing. Each type of experience was found to be described in language which reflects the social construction of reality; those with schizophrenia used words like illness, deviance, impairment and badness, while the mystic texts used religious imagery and the drug induced hallucinators wrote of expanding their minds, being out of it and similar expressions. The researchers conclude that the different types of experience are more different from each other than they are alike. This is an interesting finding since it implies that while the experience of hallucination in schizophrenia may be likened to these other, perhaps more common experiences, it cannot be fully understood by analogy.

Some interesting findings about the experience of hearing voices are presented in the report of a study by Romme, Honig, Noorthoorn and Escher (1992). After a television programme on the topic they sought study volunteers from people who hear voices. The authors remark on the usual practice in psychiatric care of bringing patients into our reality rather than our exploring theirs, a practice which often has the effect of ignoring experiences like voices which sometimes represent a large part of the patient's daily life (p. 99). Both psychiatric patients and people who had not had psychiatric care took part in the study. The report discusses the ways in which some people are able to cope with voices by distraction, ignoring, selective listening or setting limits. While a large number of respondents felt they coped well, a significant number did not feel able to cope with the voices, and the voices themselves were described as coming from different places (ie. there are different types of hallucination or pseudo-hallucination). The types of voice people heard also varied widely; some people had voices which were warm and kindly but others heard those which gave imperative instructions or dominated them. Romme et al note that patients felt significantly less supported than did non-patients, and also that patients reported significantly more often that others did not know about their voices. The latter are disturbing findings whose reasons were not addressed in the study. The researchers state "most schizophrenic patients hear voices inside their head, but are not able to have a dialogue with them and do not feel they can cope with them" (Romme et al, 1992, p. 102). This is a finding which challenges a commonly held belief amongst mental health workers that all people who hear voices can be taught to control them to some degree by cognitive effort.

Delusions are another symptom of schizophrenic illness which traditional psychiatric nursing practice regards as representing an escape from reality. Nurses are advised not to argue with clients' false beliefs, to focus on the reality-based aspects of their communication, and to protect them from acting on their delusions in a harmful way (Haber, McMahon, Price-Hoskins & Sideleau, 1992). It is also suggested that clients may be helped to avoid stressors which precipitate discussion of their delusions, and that the delusions themselves represent an attempt to meet needs that could be satisfied in more direct ways (Barile, 1984 cited in Wilson & Kneisl, 1988, p. 413).

Roberts (1991) suggests that delusions may perform a useful function for those who hold them. Roberts used a Purpose in Life Test, Life Regard Index and Beck Depression Inventory to test a group of 17 people with longstanding delusional belief systems and a diagnosis of schizophrenia or schizoaffective disorder, and three groups of controls; 17 previously deluded patients now in remission; 16 psychiatric rehabilitation nurses and 33 Anglican Ordinands. The latter were chosen as a comparison group because their faith was considered to represent a longstanding sincerely held and complex belief system which could be likened to a delusional system. Roberts acknowledges that patients with chronically systematised delusions are not common and it is therefore difficult to know how representative the group studied is, but his findings are remarkable. While in any objective sense the deluded patients have greatly inferior quality of life, their scores on the tests were comparable to those of the Anglican Ordinands.

> The chronically deluded patients in this study have been found to have a very high level of perceived purpose and meaning in life and low levels of both depression and suicidal ideation, in contrast with a comparable group of chronic schizophrenic patients in remission.
>
> (Roberts, 1991, p. 25)

The need to understand the inner experience of individuals, in context, and in its fullest sense in terms of its meaning for the person, is highlighted by findings such as these. The findings also verify the potential for people with mental illness to discuss such experiences and the way they cope with symptoms. It may well be that not only should the presence of delusions and their purpose be understood, but so should their loss when it occurs.

It has often been assumed that it is actually not possible to understand the experience of people undergoing a psychotic episode, but this assumption is called into question by innovative work by Sass (1988, 1990, 1992a, 1992b). Sass (1988) took a phenomenological approach to understanding the subjective experience of a young woman, "Renee," the author of "Autobiography of a Schizophrenic Girl." He compared her experience with modernist writing as a means of explaining and illustrating the *Stimmung*, a state in which

> The patient will stare transfixed at an alienated perceptual world that may have one or more of several anomalous characteristics. The world may seem strangely unreal; objects may seem fragmented, or devoid of standard pragmatic meanings and manifesting instead their sheer existence; or objects and events may seem imbued with a tantalising but ineffable quality of significance.
>
> (Sass, 1988, p. 223)

In his later work Sass expands on this form of analysis, using a range of work by modernist writers and artists to theorise about additional aspects of the experience of early schizophrenia.

## Insight, acceptance, self monitoring and medication

Insight is a term which is used commonly in the context of mental illness but which has several different definitions (Greenfeld, Strauss, Bowers & Mandelkern, 1989). A study into the nature of insight and interpretation of illness in people recovering from psychosis resulted in a description of insight as composed of five largely independent dimensions. The researchers interviewed people recovering from recent psychotic illness, asking them about their experience, their opinions of its cause, the treatment they received, and their expectations about the future course of their problems. Greenfeld et al propose that insight is actually composed of a complex interaction between several aspects; views about symptoms, about the existence of illness, about aetiology, vulnerability and the value of treatment. They suggest that if people are to be educated about schizophrenia such education would be best to address each aspect of insight specifically. Insight is thus not something which people either do or do not possess but rather covers a range of dimensions, while it is also something about which people are able to talk.

Acceptance of a diagnosis of illness is closely tied to problems of labelling. Lally (1989) asked how patients come to terms with the challenge to self concept which illness and psychiatric hospitalisation bring, and how they self-label. Using a mixed quantitative and qualitative design he explored the experiences of a group of 60 patients in a psychiatric hospital and the effect of their experience on self concept. His findings suggest that history, in terms of frequency and duration of hospitalisation, and experience of hallucinations both have an important part to play in "determining engulfment in the patient role" (p. 253). He recommends more research into the ways in which people come to terms with the changed sense of self brought about by mental illness and how some manage to avoid defining themselves primarily in terms of their illness.

## Life after the resolution of acute illness

A small number of studies have been conducted to examine the subjective experience of people with schizophrenia who are no longer acutely ill and who are living in the community rather than in hospital. Most of these have used quantitative or mixed quantitative and qualitative approaches, although a few have taken a purely qualitative approach.

A group of researchers conducted a follow up study of 532 patients discharged from hospital care in Harrow over a ten year period. Summing up the findings Johnstone, Frith, Leary and Owens (1991) comment on the heterogeneous nature of schizophrenia and the way this was evident in the lives and characteristics of the people they followed up. While not all the patients had fared badly, unemployment was common, as were social difficulties and a restricted life style. Many of the study participants were reported to live with continuing symptoms and to need ongoing support from relatives. High rates of self-harm, suicide and early death are noted as signs of the cost of schizophrenia.

Leary, Johnstone and Owens (1991) focused their study on social outcome and elaborate on the socially impoverished lives they discovered. In the month prior to the study 13.8 per cent of the participants had not done any shopping and 44 per cent had not entered a social gathering (such as a cafe, cinema or church) where they might make contact with others. Even more disturbing, during the same one month period over one fifth of the participants (22 per cent) had had no visitors. It is noted that 73 per cent of the people interviewed were inpatients at the time, but the picture of a less than fulfilling existence for all these people is one which begs for further study. No such work has been published in New Zealand to date.

Sometimes it is problems arising from the social dimensions of life which lead to rehospitalisation for people with schizophrenia. Hicks (1989) summarises the overall findings of a study involving twenty men and ten women readmitted to hospital less than a year after discharge into the community.

> The overall findings revealed an inadequate level of subsistence, and a stigmatized life-style fraught with crisis-precipitating events. The inability to deal with experiential problems related to role transition, living arrangements,

> financial concerns, and other people were identified as predominant factors inhibiting community tenure.
>
> (Hicks, 1989, p. 138)

Using questionnaires, semi-structured interviews, rating scales and a structured diary Wiedl (1992) studied coping in people with schizophrenia. He comments on the image of a passive patient as an inaccurate one, reporting that most participants were aware of symptoms and impairments and also that they reported significant stress in areas categorised as "self" (such as purpose in life, self definition, and self-perception) and "environment" (eg. social contacts and family). Most participants were found to be confronted by multiple stresses. Wiedl comments on the easier nature of answers given in interviews compared with those in response to questionnaires; this is a finding also discussed by Norman and Parker (1990) who asked a group of patients moving from hospital to community about their experiences. These authors write of their conviction that both the relationship of the participants and researcher and the type of methodology employed affect research with the mentally ill. They maintain that qualitative research methods using unstructured interviews and a researcher who is familiar to the participants are important in eliciting rich data with this population group.

While living in the community is often difficult it is the preferred option for many people, including the participants in Norman and Parker's (1990) study, and for the 48 discharged long-term psychiatric patients in a quality of life study conducted by MacGilp (1991). Living in the community is desirable because it is ordinary (Lorencz, 1991). Lorencz's study used a grounded theory method to examine the process of leaving a psychiatric hospital, as it was explained by four men with schizophrenia. As Lorencz points out, "becoming ordinary" is not a common aspiration amongst adults, but for these men it was a mark of success which signified their becoming "normal, productive community members" (p. 199). Those living in the community may also report themselves to be mentally well (Dzurec, 1990) and to want "to improve their physical and psychological functioning, maximise life enjoyment and to find meaning to life" (Lee, Lieh-Mak, Yu & Spinks, 1993, pp. 179-180).

An ethnography of psychiatric clients in an American community is reported by Estroff (1981). Estroff describes her experience in mixing with a group of clients to whom an intensive psychiatric treatment programme in the community was offered as an alternative to hospital care. Her research involved two years of fieldwork with clients with a range of diagnoses. Estroff describes a trap in which these clients were caught; the need to "make it crazy," from which they could find no easy means of escape. The participants in this study did not see themselves as "normal." They mixed mostly with other psychiatric clients, were very poor and many were involved in taking and selling drugs, in stealing and in suicide attempts. Their careers were those of psychiatric patients, it was by this that they described themselves and it provided for their financial support though social welfare benefits.

The findings of a study by Barham and Hayward (1991) are rather different from those just described. Using semi-structured interviews these researchers set about interviewing 24 people about the personal and social consequences of schizophrenic illness. The participants in Barham and Hayward's study spoke of their experiences of exclusion and of structural constraints which interfered with access to good housing, employment and social life. They talked of poverty and the difficulties they had in accounting for themselves to others in a climate in which they have to battle against psychiatric ideology, professional expectations and social prejudice; areas in which others have limited expectations for them. In contrast to the participants in Estroff's study, these people described their struggle to break free of "the system." Barham and Hayward note the discrepancy between their findings and those of Estroff (1981) and question whether the lessened contact with psychiatric services or changes occurring over time might account for the differences. More research into the everyday experience of people with schizophrenia is clearly warranted.

Few such studies by nurse researchers were located in the literature. Fusae Abbott (1992) investigated the life course and daily life experiences of 42 people with schizophrenia living successfully in the community. Data collection was accomplished by means of semi-structured interview, clinical records review and two questionnaires: the Modified Brief Psychiatric Rating Scale and the Life Skills Profile. The participants in Abbott's study all used strategies to manage symptoms in their daily lives, medication being the most common. Other strategies included talking, relaxation, measures to occupy their time and exercise. Daily lives were characterised by solitary indoor activities, including considerable sleeping or napping. Social activities were valued and reported as satisfying, although sexual relationships were not satisfactory for most participants and finances were a problem for many. Problems associated with work, including the expectations that people work fulltime, the intricacies and problems associated with being on a benefit and difficulties with symptoms and with job related stress all lead to considerable dissatisfaction. Abbott comments on the need to recognise that people with long term mental illness suffer from psychological stresses and worries like anyone else as well as from illness related symptoms, and notes that more research is needed to clarify the nature of the real gaps in understanding between consumers and health care providers.

Godschalx (1989) conducted qualitative interviews with 30 people with schizophrenia, asking them each in an hour long interview about their daily life, including their activities, concerns, hopes and expectations and what they found enjoyable and painful in their circumstances. A Likert scale was used to help participants describe the intensity of experiences. Security (which encompassed psychological, physical, economic and interpersonal aspects) was found to be the most desired experience among the participants. They spoke of wanting to find meaning in life through experiencing accomplishment and usefulness. The need to manage emotional pain was also rated highly - this included coming to terms with loss of ability, the prospect of not finding a partner or raising children, and the feeling that they were "not normal." In describing how they coped with their situation participants gave a range of answers including "ignore it and live," "work on getting better" and "resign self to illness." Godschalx proposes a life-focused assessment model from which psychiatric nurses might practice in order to gain a fuller picture of what the experience of people with schizophrenia is really like. As she explains

> While the diagnosis may be schizophrenia, what is wrong may be loneliness, fear of homelessness, physical vulnerability, unpredictability of and a fear of hallucinations, a sense of meaningfulness [sic] in life, or pain over loss of ability. The diagnosis does not describe what is problematic for the individual client.
>
> (Godschalx, 1989, p. 22)

A phenomenological study which examined mentally ill clients' perceptions of their illness and its effects on their lives is reported by Vellanga and Christenson (1994). The research involved interviews with fifteen men who attended an outpatient mental health clinic in the upper midwestern United States. Eight of the men had a diagnosis of schizophrenia, three of schizoaffective disorder and the remaining four had been diagnosed as suffering from a bipolar illness. The participants had lengthy histories of mental illness which both they and the researchers judged to have restricted their ability to function in their environment. Four themes are reported as reflecting the participants' lived experience: stigmatisation and alienation, loss, a pervasive feeling of distress, and acceptance, the latter entailing self acceptance and a recognition of the need for acceptance by others.

The available evidence indicates that life in the community can be difficult for people with schizophrenia. Many must cope not only with residual problems resulting from their illness, but also with an often unaccepting community, financial hardship, and an altered sense of who they are in the world. People with schizophrenia possess considerable insight into the nature of their illness and are often able to manage their lives successfully, yet researchers wanting to understand more about the illness have seldom sought their viewpoint or asked what is important to them. Instead researchers and clinicians operate out of their own theoretical frameworks without checking their perspective with that of those who know the most about the effects of the illness and the suitability of various forms of assistance. As Strauss (1989) asserts, there is room for "constructive uncertainty" in future research, for enquiring in a way that allows for information which does not fit present "hypertrophied theories" (Strauss, 1989, p. 180).

In addition, while acute episodes of schizophrenic illness are relatively short and can be dealt with fairly effectively, we know very little about the best ways to help people to deal with the longer term effects of the illness. Much more is known about the acute aspects of schizophrenic illness than about its long term course and its effect on people's daily lives. No research of the kind undertaken in the present study was found in the literature. There was no evidence of qualitative research which attempts to gain an understanding of the experience of schizophrenia from the perspective of those who are living successfully in the New Zealand community. Using a Heideggerian phenomenological approach and a nursing perspective this study was designed to begin to address this gap in the literature.

## REVIEW AND SUMMARY

This chapter began with an overview of recent trends and findings in biological research into schizophrenia. Research into such aspects as brain pathology, neuropsychological dysfunction and clinical and neurological aspects of the illness forms part of the background understanding of schizophrenic illness, informs treatment modalities and impacts on the experience of the person who lives with this, as with other illnesses. Many of the research findings are conflicting or inconclusive, but researchers are hopeful of greater understanding of the biological elements of schizophrenia in the near future.

Critics of the biological approach to research in this field signal the danger of losing sight of the person in reductionist methods, or blaming the victim through the individualising of problems. The nursing literature has only recently begun to take note of trends in biomedical research and reactions range from a fear that nursing's focus will be lost with the move of psychiatry toward this model, to a welcoming of the findings as paving the way for a more clearly defined place for nursing in the care of the severely mentally ill.

The need to be aware of wider social implications in the treatment of the disorder is a common theme in recent literature. Discussion in this chapter has referred to recent research into treatment with neuroleptic drugs and psychosocial interventions, trends in community psychiatric nursing and nursing's particular focus in the care of those with schizophrenia. There is evidence in the literature of a move away from more traditional psychodynamic models of nursing practice which require nurses to remain distant from patients, and toward models which depend on a more equal relationship between nurse and client.

Several researchers have investigated aspects of the subjective experience of schizophrenia, either in its early stages or over the longer term, while autobiographical accounts by people who have themselves experienced the illness indicate that their experiences have not yet been well understood by others. It is clear that those who live with a schizophrenic illness face many more challenges than just those related to the experience of acute psychosis. The long term effects of the illness, including others' reactions to the person who has been mentally ill, can encompass virtually every aspect of people's lives.

This chapter has served to set the present study of the experience of schizophrenia in the context of the extensive schizophrenia research literature. Few nursing studies addressing the daily lives of people with schizophrenia living successfully in the community were found, and there is clearly a need for more qualitative research in this area. The applicability of a phenomenological approach to this study and the method by which the research was conducted will be discussed in Chapter Three.

# CHAPTER THREE

# STUDY DESIGN AND METHOD

The purpose of this chapter is to discuss the use of phenomenology as a method of enquiry into the lived experience of schizophrenia and to explain the procedures by which this study was carried out. A brief introduction to the study participants is given, and the structure of the data chapters which follow is outlined.

The phenomenological approach taken in this study is based on the work of Martin Heidegger, particularly Division I of "Being and Time" (1927/1962). It is from the ontological question regarding the nature of Being that Heidegger's phenomenology derives. In Chapter One I presented an introduction to Heidegger's ideas and their relationship to notions of personhood and the way in which we know the world. Heidegger's philosophical discussion overturns the Cartesian division of mind and body, self and world. Instead of existing as objects in an external world, we are always intimately and inseparably wedded to the world. The world both constitutes the self and is constituted by it. From this position there is no possibility of our ever obtaining an objective or "outside" view of the world or of things in the world. The traditional approaches of "objective" science are not appropriate to this world view, since there is no way of stepping back to gain an objective view of things. The possibility is simply not open to us because of the nature of human existence.

In Heidegger's view understanding of the world rests in interpretation. Interpretation is the development of understanding. "In interpretation, understanding does not become something different. It becomes itself" (Heidegger, 1927/1962, p. 188). It is in making it explicit that something is interpreted. Heidegger gives the example of seeing something *as* a table or *as* a door; it is in grasping something before us *as something* that we understand it explicitly; we comprehend what it is for or what it means.

> That which is disclosed in understanding - that which is understood - is already accessible in such a way that its 'as which' can be made to stand out explicitly. The 'as' makes up the structure of the explicitness of something that is understood. It constitutes interpretation.
>
> (Heidegger, 1927/1962, p. 189)

Implicit in this explanation is reference to the circular nature of understanding. Interpretation is always grounded in prior understanding; in Heidegger's terms it is founded on fore-having (something we have in advance), on fore-sight (what we see in advance), and on fore-conception (what we grasp in advance). Whenever we interpret something we rely on our prior understanding, on our assumptions, on that which has been taken for granted beforehand. "Any interpretation which is to contribute understanding, must already have understood what is to be interpreted" (Heidegger, 1927/1962, p. 194). There is no way of deepening our understanding of something in a way which is entirely free of our prior assumptions about it. "An interpretation is never a presuppositionless apprehending of something presented to us" (Heidegger, 1927/1962, pp. 191-192). Thus interpretation depends on prior understanding and understanding depends on interpretation. Heidegger stresses (p. 195) that this cyclical character of understanding should not be seen as a vicious circle. Rather, it is an unavoidable consequence of the nature of Being. What is important is not to try to avoid the circle, but to enter it in the right way.

> In the circle is hidden a positive possibility of the most primordial kind of knowing. To be sure, we genuinely take hold of this possibility only when, in our interpretation, we have understood that our first, last, and constant task is never to allow our fore-having, fore-sight, and fore-conception to be presented to us by fancies and popular conceptions, but rather to make the scientific theme secure by working out these fore-structures in terms of the things themselves.
>
> (Heidegger, 1927/1962, p. 195)

In working the hermeneutic circle the phenomenologist endeavours to strip away layers of assumption and "popular conceptions" through which things are commonly explained, in order to reach "the things themselves" and to elucidate them in a new way. As Packer and Addison (1989) explain, the circularity of understanding is made up of two movements. The first, which they describe as a forward arc, and in which we try to study something, involves both understanding and misunderstanding; we have some preliminary understanding and "we inevitably shape the phenomenon to fit a 'fore-structure' that has been shaped by expectations and preconceptions, and by our lifestyle, culture and tradition." If we remain open and persevere in our attempts to understand, our attention will be drawn to the presuppositions we held about the phenomenon under study. In the second movement, the backward arc, "we gain an increased appreciation of what the fore-structure involves, and where it might best be changed" (Packer & Addison, 1989, pp. 33-34). It is in proceeding through this, the hermeneutic circle, that understanding is deepened.

What is sought in this movement within the hermeneutic circle is a deeper understanding of truth, not in an absolute sense, but in the form of an answer to the practical or existential concern which is the focus of inquiry. Given the nature of existence, no absolute, timeless, validated knowledge is possible. Indeed Heidegger points out that no account of things can remain true for all time, since eventually any account of a phenomenon begins to lose its ability to make the phenomenon stand out from the background (Packer & Addison, 1989). It is this "standing out from the background" which constitutes the second essential element of phenomenological inquiry.

The examination of words and their derivations, along with the use of many unusual hyphenations is characteristic of Heidegger's writing. Bollnow (1974) points out the importance of Heidegger's interpretation of the Greek word *aletheia*, truth, as *a-letheia*. This combination of the privative prefix "not" with the verbal stem "to escape notice" or "to be concealed" emphasises Heidegger's negative concept of truth as "unconcealment." If truth is something which must be unconcealed it would appear that it is something which is not apprehended in an unproblematic way, that truth does not just present itself to us as it is. This is precisely what Heidegger explains to be the case. In Bollnow's explanation:

> Truth as unconcealment means that there is not at the outset a situation of some sort of knowing from which one then begins unrestrictedly to build knowledge or acquire truth. Rather, at the outset there is the situation of concealment and one must wrest the truth from it in an explicit exertion. One must rend the veil from truth. (Bollnow, 1974, p. 9)

Essentially phenomenology is this project of "rending the veil from the truth." Heidegger (1927/1962, 1977) claims that phenomenology is needed precisely because phenomena are so often covered up. "Being covered up is the counterconcept to 'phenomenon' " (Heidegger, 1927/1977, p. 84).

Heidegger explains that the Greek origin of the word phenomenon comes itself from the verb *phainesthai*, meaning "to show itself." Tracing the roots of the words further, he finds the word *pha*, "light" or "brightness." The meaning of phenomenon, then, is "what shows itself," "what is manifest." Phenomena are the totality of what lies in the light of day or can be brought to light (Heidegger, 1927/1977, p. 75).

It is in returning to the things themselves, in seeking to examine human experience in the world in which it is lived, that phenomenology aims to increase understanding about the nature of human existence. The phenomenological method aims to bring to the light of day the essence of things which have been apprehended as deceptive appearances (Bollnow, 1974), to uncover essences which have been concealed, buried over or distorted (Heidegger, 1927/1977).

> The term "phenomenology" expresses a maxim that can be formulated: "To the things themselves!" It is opposed to all free-floating constructions and accidental findings; it is also opposed to taking over concepts only seemingly demonstrated; and likewise to pseudo-questions which are often spread abroad as "problems" for generations.
>
> (Heidegger, 1927/1977, p. 74)

Phenomenology thus entails a questioning of assumptions, an attempt to go back beyond theoretical explanations and conceptual schemes, to return to the things themselves. The aim is to present an account which reveals the phenomenon in question in a new light, one which makes it stand out from the background, which enables us to grasp it in a new way. Heidegger emphasises that the term phenomenology refers primarily to a concept of method. His position is that phenomenology's concern is with people in their "average everydayness" (1927/1977, p. 60). It is his contention that any kind of technical devices should be avoided and that the procedures by which a phenomenological investigation are carried out should be appropriate to the question involved.

> The way of encountering Being and the structures of Being in the mode of phenomenon must first be *wrested* from the objects of phenomenology. Thus the *point of departure* of the analysis, the *access to* the phenomenon, and *passage through* the prevalent coverings must secure their own method. The idea of an "originary" and "intuitive" grasp and explication of phenomenon must be opposed to the naivete of an accidental, "immediate," and unreflective "beholding."
>
> (Heidegger, 1927/1977, p. 85)

The fit of phenomenology with many questions in nursing, and with the person-centred, contextual approach which nursing entails is now well accepted in the discipline. Numerous nurse researchers have used the method (eg. Banonis, 1989; Beck, 1992; Benner, 1984; Benner & Wrubel, 1989; Diekelmann, 1992; Gullickson, 1993; Kondora, 1993; Madjar, 1991; Rather, 1992; Santopinto, 1989; Tanner, Benner, Chesla & Gordon, 1993). As Munhall (1989) observes, phenomenology emphasises the centrality of subjective reality in human experience and offers a method by which nurses can investigate concerns which are neither simply material, nor easily observable nor measurable. The congruence between the approach required by the method and that of clinical nursing practice, in its dependence on an intense interaction between the researcher and participants similar to that found in clinical nursing practice, is also now well established (eg. Benner 1984; Benner & Wrubel, 1989: Taylor, 1993; Watson, 1985; Wilkes, 1991). Thorne (1991, p. 183) suggests that the relationship between researcher and participant in phenomenological research parallels "a concern within clinical nursing for the moral value of engaging in interaction with individuals as unique beings deserving of some equally unique caring or intervention."

In the context of this study it is interesting to note that there is also a school of thought amongst psychiatrists, in Europe particularly, that phenomenology is a useful tool in practice. This is reflected in the writing of Jaspers (Schilpp, 1957), Binswanger (1963), Laing and Esterson (1964) and several others. Davidson (1992) provides an extensive list. Perhaps it is not surprising considering that psychiatry has always depended very heavily on patients' self reports in order to come to a diagnosis, and to effect some forms of treatment. Binswanger (1963, p. 211) suggests that psychiatry "does not inquire merely into particular regions of phenomena and fact to be found 'in human beings,' but, rather, inquires into the *being* of *man as a whole*." His argument that the concept of a person as a physical-psychological-spiritual unity does not adequately address human experience is very similar to many heard in nursing in recent years.

In spite of the wealth of research and theoretical or philosophical discussions about phenomenology in the nursing literature there is little in the way of guidelines as to exactly how phenomenological research ought to be conducted. This is to be expected given the range of philosophical positions of the many phenomenological writers, and the nature of phenomenological inquiry itself. What is most important is that researchers explain the procedures used in their own studies and their grounding in the particular philosophical position which underpins the research. As Oiler (1986, p. 79) states, "researchers should not be restricted except by the fundamental themes that distinguish phenomenology as a movement. An increasingly thorough study of primary resources is therefore critical to the successful interpretation of phenomenological method."

Van Manen (1989, 1990) suggests that writing is the method of phenomenology. It is therefore essential to practice phenomenology in order to understand it. The hermeneutic method of interpretation (of text) is central to phenomenological research, the text being material gathered from interviews and from the researcher's notes made during the course of data gathering and analysis. Interpretation aims at "a progressive uncovering and explication (which is, of course, never fully completed) of the researcher's practical understanding of what is being studied" (Packer, 1985, p. 1089). As Benner (1985, p. 6) explains, the researcher aims to uncover meanings embedded in everyday practices in a way which avoids their distortion or destruction, and which prevents their being decontextualised, trivialised or sentimentalised. While suggesting that the methodology "is more a carefully cultivated thoughtfulness than a technique" (1990, p. 241), van Manen (1990, pp. 30-31) identifies six research activities as comprising the basis of hermeneutic phenomenological research. These activities are not to be seen as a procedural list, but rather act together in a dynamic way as a study progresses. The six elements of the method are:

(i) *turning to a phenomenon of interest.*

This process involves identifying one's concern about a phenomenon; orienting to it in terms of one's vantage point - in this study my concern is *as a nurse* - formulating the research question; and explicating assumptions and preunderstandings.

(ii) *investigating experience as it is lived rather than as it is conceptualised*
In order to examine an experience as it is lived the researcher endeavours to gain access to the phenomenon unencumbered by interpretations or theorising. It means examining one's own experience, enquiring into the use of words and idiom, reading literature and examining other art sources, and conducting interviews and observations with people who can describe the phenomenon in its everydayness.

(iii) *reflecting on essential themes which characterise the phenomenon*
During data analysis the researcher aims to grasp the essential meaning of the phenomenon, to identify themes which characterise the experience in order to be able to communicate the meaning of the phenomenon.

(iv) *describing the phenomenon through writing and rewriting*
Van Manen's contention that writing is the method of phenomenology has already been referred to. Writing is necessary to "bring to speech" (p. 32) that which is to be communicated. Writing is also a way in which "we measure our thoughtfulness" (p. 127). Through writing, ideas are set out from us and so can be reflected on. Writing is an act of self-consciousness which better enables us to see that which we wish to say and then to engage in a process of questioning. "To be able to do justice to the fullness and ambiguity of the experience of the lifeworld, writing may turn into a complex process of rewriting (re-thinking, reflecting, re-cognizing)" (p. 131).

(v) *maintaining a strong and oriented relation to the phenomenon*
Throughout the research process the researcher must stay firmly centred on the question which drives the research, resisting the temptation to theorising or abstraction. Because I entered this study with a nursing orientation while the study itself focuses on the experience of those who are nursed, I have had two orientations to maintain; the nature of the phenomenon for the people who experience it and the meaning of this focus for nursing. Maintaining a strong, oriented relation includes the production of what van Manen (pp. 151-152) describes as "strong, rich, deep and oriented text" which will have meaning for nursing action.

(vi) *balancing the research context by considering parts and whole*
This process involves a frequent shift in perspective between parts and whole: between the way the question is set forth and the answers provided; between the

parts of the text and the whole argument; between interview material and interpretive comment, and between the data and the manner of reporting the research. Under this heading van Manen also offers a variety of suggestions regarding the presentation of a phenomenological study, whose aim is to uncover aspects of human experience which provide new possibilities, in this case for nursing action.

In conducting this study I have been guided largely by the writings of Heidegger (1927/1962) and of van Manen (1990). Rather than attempt to set out any more of the guiding principles separate from details of the study, I will refer back to Heidegger, van Manen and other authors in the course of explaining the procedures employed in this research.

## Aim of the study

As van Manen (1989) explains, phenomenology involves identifying a phenomenon of concern, recasting this concern as a question and then undertaking various kinds of interrogation of the phenomenon in order to elucidate its nature and meaning. In a phenomenological account the researcher aims to provide a rich, evocative and poetic description which sheds light on everyday experience, enabling us to grasp the phenomenon in a way we have not previously seen it (van Manen, 1990). Steiner (1978, p.144) describes the Heideggerian hermeneutic as a way of seeking "to 'hear' the *pneuma*, the breath of hidden spirit in language."

The aim of the study was to describe everyday life as it is experienced by people with schizophrenia, to gain some insight into this way of Being-in-the-world. The research question became "What is it like to live with schizophrenia?"

## The choice of the phenomenological method

As discussion in the previous chapters has shown, there are multiple explanations of the nature of schizophrenic illness, some based on research, others on theoretical interpretations. The vast literature, however, has done little to advance understandings of many aspects of the illness, in particular the subjective experience of those who live with it. A growing theme in the literature reflects this gap in understanding and writers from a variety of disciplines are calling for attention to the subjective experience of those with schizophrenia. Nursing's concern with the experience of illness rather than the diagnosis and cure of disease, and its emphasis on health as well as illness, in many ways depends on an understanding of subjective experience.

The recognition that there is an aspect of schizophrenia which is not well understood implies that it has, in Heideggerian terms, been covered up. Phenomenology provides an approach by which this experience might be uncovered and brought to the light of day. As a research method it requires that the multiple theoretical explanations are set aside; it is indeed possible that they have played a part in the covering up. As Bollnow (1974, p. 9) describes it, theories and conceptual schemes may be part of the "thick fog [which] hides the true essence of things."

Although some researchers have attempted to understand the experience of schizophrenia through quantitative methods, the epistemological foundations of these approaches do not allow for the researcher to listen as openly to the perspective of the participants and to take their direction in the development of the study as do qualitative approaches. Phenomenology requires that the researcher return to the things themselves, approaching the question "with a sense of awe, empathy and appreciation" (Swanson-Kauffmann & Schonwald, 1988, p. 104). The central focus of phenomenology revolves around issues of existence, of an individual's relation to the world and to others (Spinelli, 1989).

In this study it meant that people who have the experience of living with schizophrenia were asked about their experiences, their illness and its effects on their everyday lives. Phenomenology concentrates on lived experience and it is this experience which was the focus of the study. To ask people about their experience, their Being-in-the-world, is consistent with Heidegger's account of the phenomenological approach. A search for the phenomena of interest in their ordinary "thatness" and "whatness," their average everydayness, is emphasised by Heidegger as the quest in phenomenology. The researcher approaches people in their own environment, asking them about their perspective of their experience rather than developing questions from a prior theoretical framework.

> Insofar as Being constitutes what is asked about, and insofar as Being means the Being of beings, beings themselves turn out to be what is *interrogated* in the question of Being. Beings are, so to speak, interrogated with regard to their Being. But if they are to exhibit the characteristics of their Being without falsification they must for their part have become accessible in advance as they are in themselves. The question of Being demands that the right access to beings be gained and secured in advance with regard to what it interrogates.
>
> (Heidegger, 1927/1977, p. 47)

### Recognising assumptions and preconceptions

Part of ensuring right access to the phenomenon under investigation involves becoming aware of the presuppositions one brings to the inquiry. As has been discussed, this is not a single step process, but rather proceeds throughout the study; in data collection, data analysis and writing. In the hermeneutical method one cannot simply declare one's assumptions and then put them aside. My experience and understanding is that the process must be repeated over and over again. In order to prevent one's assumptions from getting in the way of the data, and of a grasp of the phenomenon, it is necessary to revisit those assumptions as they change over the course of the project. As the study proceeded, every time I thought I understood something I had to ask what I had assumed to be so, or not so; whether the data communicated the idea; whether I had closed off my seeking too early.

As I began the study I was able to recognise some of the preconceptions I had about schizophrenia and about the lives of people who are diagnosed as suffering from the illness. At this stage I believed schizophrenia to be a chronic mental illness in the majority of cases, one from which most people do not fully recover. I thought that to offer hopes of cure or of a complete return to life as it was before the illness was to set people up for failure and disappointment. I imagined life with the illness to be a lonely one in which people were often in need of support, but one which people generally managed fairly well in their own terms. There seemed little doubt that many people with the illness lived on social welfare benefits and that their opportunities in life were limited by their finances. I had heard many talk of boredom.

I believed that psychotic illness was a frightening event, and that when people with the illness asked for help they did so out of a genuine recognition of their own need. This belief was one not supported by some clinical nursing colleagues who believed that help-seeking was a manifestation of dependency. Since I felt that those asking for help were in real need, I believed that a friendly, open approach was appropriate and felt uncomfortable about the distance which I observed some nurses maintain between clients and themselves. I did not favour either a behavioural or an insight oriented psychotherapeutic approach with this group of clients. I considered that human relationships were important for people with schizophrenia, and that even when it was difficult to understand what people said when acutely unwell it was important to communicate a willingness to try to relate to them. In this respect I felt that health professionals, and especially nurses, have a particular responsibility to be kind and respectful and that they play an important part in the lives of some people with the illness.

That there was something more which could and should be known about life with schizophrenia was also an assumption I held strongly at the outset of the study. I believed there was a question to be asked and that it was possible to obtain some kind of an answer. While this sounds in some way self evident, I have been challenged that the study was impossible, either because people with schizophrenia "do not know what is true" or because they might be unable or unwilling to share their experience and their understanding with me.

One of the most helpful ways in which my assumptions were demonstrated to myself in the course of the study was through questions, comments and challenges from people to whom I spoke about it, including my study supervisors. Through challenges, which were sometimes provocative, I was made to see not only some of the assumptions I held, but also several which I did not. The assumptions I did not hold pointed me not only to those I did, but also to ideas in the wider community which are relevant to the world in which the study participants live. Some of the deeply rooted assumptions about mental illness which are held in our society have been addressed in the earlier chapters of this thesis.

## Access to study participants

Van Manen (1990) suggests that in conducting a phenomenological investigation there are several sources of data, among them personal experience, words and idiom, and the "borrowing" of other people's stories. In conducting this study I have not been able to draw on all these sources of data. I have never had direct experience of a schizophrenic illness, but have nursed people who have had the illness. Thus my personal experiences in the area are confined to what I have observed in others and to my experiences as a nurse. For the major part of the data in this study I have had to depend on collecting descriptions of the experiences of others.

Because no absolute truth is sought and no mathematical probabilities are involved, there is no attempt made in phenomenological research to find a representative sample of participants. Instead one looks for a range of stories from those who have lived the experience. The inquiry aims not so much at reflecting the point of view of the participants themselves, but rather at what their experience points to in what is an essentially human experience (van Manen, 1990).

In order to gain access to the phenomenon I wanted to investigate - the experience of schizophrenia and its effects on everyday life - I sought participants who had been diagnosed as suffering from schizophrenia, were well maintained on medication and were living in the community. Since the aim of the study was to examine the experience of living with schizophrenia, rather than coming to terms with a relatively recent diagnosis, teenagers were excluded and I aimed to find participants who had lived with their diagnosis for at least two years. All participants were to be competent in the English language, both to ensure informed consent to take part and to enable their stories to be understood.

In stipulating that the participants must be well maintained in the community, my aim was to avoid initial contact with any potential participant who was psychotically disturbed, since he or she could not be considered at that point able to give informed consent. I recognised that it was possible that one or more participants might become unwell during the course of data collection and planned, if this should occur, to determine with them the course to be followed. I expected to keep some form of contact (such as visiting the person in hospital) so long as the participant wished. In fact this situation did not arise.

Participants were sought in a two stage process. I first approached office holders in the Schizophrenia Fellowship, a nationwide support group which exists to assist people with schizophrenia and their families, and asked if they would seek potential participants for me. I felt that in this way the interests of the participants would be protected, in that their names would be suggested as possible participants by a member of a group specifically designed to assist them and their families. Contact was made with Schizophrenia Fellowship in three different geographical locations, my intention being to select participants from a range of different living circumstances and, more importantly, to assist in maintaining participants' anonymity.

As potential participants were identified and ther names given to me I telephoned them, explained the study briefly and arranged to meet and discuss it more fully. At this point the potential participants were given an information sheet outlining the purpose of the study, what I was asking of them, and detailing their rights if they agreed to take part. Written consent was obtained from each participant before interviews began.

In total 10 adults, 7 men and 3 women, took part in the study. Their ages ranged from 21 to 64, their occupations, paid or unpaid, included a painter, a writer, an academic and an educator for a voluntary organisation. Some participants were unemployed. All had been diagnosed with schizophrenia at least two years prior to my meeting them; in fact one had been living with it for over 40 years. All participants were living in the community, most in their own homes, although four were in supported or supervised accommodation. All regularly took some kind of antipsychotic medication. A profile of each of the participants is presented later in the chapter.

Two of the participants had heard me talk about the research at meetings of Schizophrenia Fellowship and approached me directly to volunteer to take part. A third potential participant heard about the research from a friend and was keen that I interview him when he was well enough. However, in his own judgement he remained unable to participate during the period of data collection. Two people who were approached decided not to take part, and, as I was uncertain of her meeting the criteria for inclusion in the study, I did not include one candidate who was unclear about her own diagnosis and who did not receive any kind of regular medical or nursing follow up.

## Ethical considerations

Ethical concerns directed several of the criteria for participant selection and the method by which contact was made. Prior to the commencement of the study the research proposal was submitted to the Massey University Human Ethics Committee for ethical approval.

Because of their mental illness all of the study participants might be considered to be especially vulnerable. To ensure that I was able to obtain informed consent for the study I arranged, except in the two cases where I was approached directly, for an intermediary to tell potential participants about the study and to ask if they would be interested. This person supplied me with names and telephone numbers only after potential participants had agreed to my contacting them. In other circumstances I would have chosen to have the participants contact me, but I felt in this case that being asked to make a telephone call was more stressful than agreeing to answer one which was expected. If interest was expressed during this phone call, I then made arrangements to meet the person. The study was explained in more detail and an information sheet (Appendix I) outlining the study and the participant's rights, along with my work address and telephone number, was given to the person. Each participant was given the opportunity to consider their willingness to take part in the study before signing a consent form (Appendix II), although several wished to begin the interviews at our first meeting.

Interviews were conducted at a time and place which suited the participants. Before each interview I telephoned to check that the participant was willing to speak to me and that the appointment was still suitable. I regarded consent as an ongoing process; participants were aware that I had agreed to answer any questions they wanted to ask, that they could refuse to answer any question or turn off the tape recorder if they wished, and that they could withdraw from the study at any stage.

Each participant had my university contact address and telephone number at the beginning of the study, although quite early into the study I decided that I would also give them my home telephone number. This seemed fair by way of reciprocity; participants had invited me into their homes and were open and honest about their lives; it also made contacting me easier as it eliminated the necessity to negotiate a switchboard. In addition it had become clear to me that the speech patterns and verbal delivery of some participants was unusual enough that their leaving a message at work could actually serve to identify them as study participants.

In other ways also maintaining anonymity and confidentiality for the participants was a more complex challenge than I had anticipated. Although they were promised that pseudonyms would be used, many participants expressed their lack of concern over this, and asked that I use their real names. I discussed some of the problems this might cause with participants and decided to disguise the identity of participants in the final report. Some participants offered their own pseudonyms. Given that these were names by which others might have known them (for example some proffered a favourite nickname) I have instead used names I have chosen. However, it is not only by names that the participants might be identified. In a country as small as New Zealand I believe there are some other details about participants which might identify them and have endeavoured to conceal those details as far as I believe necessary. The wide geographical spread of participants, from both cities and small towns and from Auckland to the lower South Island has also helped to minimise the possibility of the participants' being identified.

Because I used intermediaries to contact most participants, these people knew the identity of several of the people in the study. They did not, however, know who had agreed to participate unless the participant told them. I soon discovered that several participants had chosen to tell friends, flatmates or fellow workers about their part in the study. One advantage of having an intermediary know of the study was that the participants had someone else to discuss their participation with and who could act as an advocate if they wished, while I had someone with whom I could raise concerns if I were extremely worried about the health of any participant. To my knowledge no participant did have problems in terms of their participation, but I did ask one of the intermediaries to call on one study participant after she had told me of severe financial problems at one visit.

All participants were offered transcripts of their interviews if they wished. Only two participants took up this offer at the time, although one phoned me a year after I had last seen him, requesting a copy of his interview tapes to use in a broadcasting project. He has the tapes and copies of his transcripts but the radio programme never went to air. The first participant to receive his transcripts back expressed some concern at the number of pauses, "ums" and "ahs," and repeated phrases in the verbatim transcript. To avoid embarrassing or hurting participants I subsequently edited those transcripts which were given to them, to remove false starts and so on, while retaining the sense of the original conversation. The purpose required of the two sets of transcripts was slightly different; I wanted to be reminded of the entire context and manner of speech of the participants, and indeed of my own verbalisations, while the participants wished to retain a copy of the interview as a reminder of their own experience and to check whether they had anything to add or delete from the record. Several participants in the study gave me samples of their writing or artwork. A special consent form (Appendix III) was signed to record their agreement to my holding this material.

Each of the participants invited me into their home during the course of the study, most also offering me food and drink. In return I was asked by some to drive them to town or to visit friends, and I sometimes brought morning tea or flowers or vegetables from my garden when I visited for interviews. I found I was often asked, and answered, personal questions about my life as well as those about the study.

Given the need of the participants to form a trusting relationship with me as researcher, I anticipated that data collection would commence slowly at first, and would last over a period of several months for each participant. Similarly the termination of contact was to proceed slowly rather than abruptly. In fact each of the participants really set their own pace both for the initial sharing of information and for the time at which our relationship terminated.

## The Study Participants

As has been indicated, the study participants came from a range of different ages and backgrounds. A general outline is given here, indicating their age, living circumstances and medication at the time they were interviewed. Each of the participants admitted to having been diagnosed as having schizophrenia, although as will be shown in the data chapters which follow, they did not all completely agree with this diagnosis. Some participants had medication changes during the course of the study; the details given here are those I was told, usually at the commencement of the study. I have recorded drug dosages when they were told, or shown to me, but some participants did not know doses; the information they did give is recorded here. A glossary of drug names and actions is included as an appendix. Pseudonyms have been used for all participants.

**Roger** was 42 years old when I interviewed him and was first diagnosed with schizophrenia 20 years ago. A single man, he lives alone in his own flat, bought for him by his family. Roger has seldom worked, except for a brief time after leaving secondary school, living instead on an invalid benefit. He takes haloperidol 15mg; lithium carbonate 1000mg, and two tablets of procyclidine daily in divided doses. Roger was born with congenital limb deformities which have presented problems all his life, while a stammer made his speech quite difficult to understand, especially when he was nervous or excited.

**Simon** was in his early fifties, a divorced father of two school age daughters. He works fulltime as an academic, and lives in his own house. Simon first became ill some 25 years ago, and now takes Melleril (thioridazine) 50mg daily.

**Judith** was 35 years old, and lived with her partner and 9 year old daughter in a rented flat. She receives a social welfare benefit. Judith had recently changed from Stelazine (trifluoperazine) to perphenazine but was uncertain of the dose. As will be discussed in the following chapters, Judith's medication regime was quite erratic, partly because of her uncertainty about her illness. She was unclear as to the exact timing of her diagnosis of schizophrenia but thought it was approximately two to three years before I met her. A severe accident with resulting limb trauma has also had a significant effect on her health and her lifestyle over the past few years.

**Adrian** was 38 years old, a single man who was living in supported Trust housing with two older men. Adrian had been diagnosed as having schizophrenia 7 years before, though he did not wholly concur with this diagnosis. His illness interrupted his working career; he now receives a benefit and works part time as a salesperson. I noted a distinctive gait and some unusual and repetitive body movements; Adrian commented on the latter as a physical problem for which he has been seeking help, unsuccessfully. Adrian receives depot medication; Modecate 12.5mg every two weeks was changed during the course of interviews to 25mg every three weeks, with the addition of oral chlorpromazine 50mg. The latter was prescribed, he told me, to help increase his weight.

**Jack** was a confirmed bachelor who liked hunting, shooting and fishing and lived alone in a house left in trust for him by his father. He was 64 years old and had first become ill at twenty two. He has had several manual jobs in the past and done well at them by his account. Jack now has a number of physical problems, including failing eyesight, although he claimed not to be very troubled by most of them. He asked me to read the labels on his medication bottles as they were too small for him to see and told me that his doctor had changed his medication and that he was now on chlorpromazine (50mg bd[1]). As far as I could tell from the multiple containers he also took (or had now discontinued) Orap (pimozide) 2mg bd; Serenace (haloperidol) 3mg at night; and Nozanin (methotrimeprazine) 25mg as well as Betaloc, frusemide and Prazosin. Jack was not clear about which tablets he took when, but was visited regularly by a community nurse who set out his tablets in a dispenser.

**Nick** was 27 years old and first became ill approximately eight years before I met him. He was living in a supervised house run by the local Area Health Board, along with three other residents at the time I met him, and had been there for three years at that time. Nick's medication was Trilafon (perphenazine) and Tegretol (carbamazepine) tablets morning and night, but he was unable to tell me the dose; his medication is dispensed by the resident home supervisor.

**Liz** was 27 years old and lived with her fiance in a small flat in a supervised residential complex at the time I met her. She was working part time for a voluntary organisation and also received a benefit. Her illness began four or five years before, although she was not diagnosed with schizophrenia until after a second hospitalisation some three years before I met her. Her medication was Depixol (flupenthixol); she received a 30mg injection every four weeks. Liz's fiance also has a schizophrenic illness.

**Michael** was the only study participant who was married. He lived with his wife and two children in his own home. He was 46 years old, and had first been diagnosed as having a schizophrenic illness after an acute episode 6 years before, although he believed he had been unwell for a much longer time. His medication was Stelazine 4mg. Michael receives a benefit and his wife supplements their income by working part time.

---

[1] The abbreviation bd is a contraction of the Latin *bis in die*, and signifies that the drug is taken twice daily.

**Lucy** turned 21 during the course of interviews. She has been unwell since she was in her mid teens. Lucy lived at home with her parents, although was making efforts to break away from home and often spent time away, especially with one of her sisters, with whom she was very close, both in age and emotionally. Lucy worked part time in a shop on a voluntary basis, living on a social welfare benefit and supplementing her income through the sale of her own art work. Her medication consisted of haloperidol 15mg; Tegretol slow release 600mg; Prozac; and procyclidine.

**Chris** was a 36 year old single man who shared a house in a Trust complex with two other adults. He became ill when he was a university student and had had to withdraw from his studies as a result. Chris had a number of responsibilities with the Trust including writing for their regular newsletter. He, too, was on an invalid benefit. Chris received an injection of Haldol 100mg every four weeks and found he had to take regular Cogentin to counteract the side effects of his antipsychotic medication.

## DATA COLLECTION

Multiple sources of data are used in phenomenological research. While the primary data source was interviews with the study participants, I also collected paintings, an autobiography, two autobiographical novels, photographs and a collection of poetry as well as observations recorded in field notes. Most of these data were given to me by the participants, but several other people volunteered published or unpublished work, or gave me contacts from whom to request these. In addition, while the study progressed there were television dramas, documentaries and news items, magazine articles and newspaper reports about schizophrenia, each of which added to my knowledge of the range of perspectives regarding the illness, and two films released during this time, "Benny and Joon" and "The Fisher King," each featured people with mental illness as leading characters. My own clinical nursing background and my familiarity with the health care system and kinds of treatment people with the illness might expect was invaluable in the interview process, although as I have previously mentioned, I was at a disadvantage in understanding the participants' experience since it is one I cannot share.

Interviews with participants were conducted over a sixteen month period from October 1992 to January 1994. Most participants asked that interviews be conducted in their own homes, although two held interviews at work, later asking me to visit them at home. The surroundings in which I found myself for these interviews varied widely in their style and their state of repair. I visited comfortable houses and one very untidy and unorganised one in which the occupant's home help was barely adequate to maintain a safe level of hygiene. Other participants lived in a variety of sizes of flats, from one which was tiny and cramped to one which was half a house. The supervised housing was also quite different, depending on whether the residents were required to take care of housework and gardening, or whether a live-in supervisor was able to oversee progress on these daily tasks.

All participants made a real effort to make me feel at ease when I visited. All but two of them regularly offered me tea or coffee; I have no way of knowing whether it was coincidental that the latter were two of those participants who lived in supervised accommodation. Several interviews were held with others whom the participants had invited to be present. Michael's wife joined in on several interviews, for example, while Jack often asked friends to visit while I was there, or called me to speak to his friends on the telephone. I also had occasion to join him on a visit to see one of his friends. Since several participants asked me to drive them somewhere or to walk with them to shops or out for coffee, I also had the opportunity to observe them in other surroundings and to watch how others interacted with them. Thus not all data collected from the participants were in the form of audiotaped interviews; observation, recorded in field notes also contributed to the data.

The length of interviews varied according to my judgement of the capacity of the participant to respond and his or her apparent interest in continuing. Interviews lasted about an hour on average, but ranged from twenty minutes to two and a half hours. I visited participants between three and ten times each over the course of data collection. Participants were asked to suggest suitable times for further interviews if they were interested in continuing; it was most common that they suggested a weekly meeting, at the same time and place. In all, I collected 57 hours of taped interviews and spent a further 80 hours with the participants during which time our conversations were not tape recorded.

Because the question of how it is to be schizophrenic in the world is such an all encompassing one, the participants in the study could not tell me about it directly at first. Rather, my questioning, in the form of conversational interview, ranged over a broad spectrum of topics relating to life in general. I endeavoured to obtain some basic demographic data at first interview, to ask about when the person first was diagnosed as having schizophrenia and how their illness has affected their life. Questions followed the lead of the participants rather than a prearranged schedule, although I attended each interview with a general list of subject headings or areas for discussion. I wanted to know, for example, about their illness, their social and working life, their relations with other people, their leisure activities, future aspirations, daily activities, medication and side effects.

I was very conscious throughout the interview process of the potential to "lead the witness" and of the way in which closed ended questions lead to brief answers, or how a train of thought was all too easily interrupted if I spoke too soon. On the other hand too long a pause clearly left participants uncomfortable. Each subsequent interview began with a summary of the main points of discussion from the previous one, and I offered tentative interpretations at this stage if I had formulated them. The self consciousness which is evident in such situations is described by Swanson-Kauffmann and Schonwald (1988, p. 102):

> Because informants must speak freely and reflectively about experiences that may not be easy to discuss, the researcher must help them dig deeply into thoughts that may not be a part of their everyday awareness. This type of data soliciting demands that the researcher move into a mode of being that is (1) hyperattentive to the informant's words and gestures; (2) totally believing that the informant is an expert on the topic of inquiry by virtue of the fact that he has lived his own experience of the phenomenon studied; and (3) on-the-spot creative in assisting the informant to reflect on the meaning of events as they are discussed. Such hyperattentiveness, belief, and creativity are all reliant on the researcher's self-engaging in the data-gathering process. In effect, the researcher's role is to move back and forth between intuiting and verifying with the informant as the informant's story unfolds.

By virtue of their illness each of the participants has had a good deal of experience in relating symptoms, dates of illness and so on to health professionals. Several participants were proficient in the language used by health care providers to describe signs and symptoms, and some were able to repeat lists of desirable behaviours they had been taught by nurses, social workers and others. When I heard these verbalised I felt that we were in the realms of theorising rather than direct experience. That most of my questions were able to have participants direct their attention to areas of their experience for which they had no slogans or preformulated explanations was evidenced by the comment made by several that they had never been asked questions such as those I was asking, or that the answers required some thinking about because they had never thought of the topic in a particular way before. Both the spontaneity of answers and the thoughtfulness with which participants attended to many questions lead me to believe that these were indeed addressing their experience as they live it.

Because the data collection phase lasted over a lengthy period most of the participants and I got to know each other well. As is true of all human relationships, I found some of the participants easier than others, and I dare say some of them liked me better than did others. Those who proved to be the most useful in terms of data, however, were not necessarily those who were easiest to talk with, or those whom I had expected to be most helpful. One young man, for example, was unable or unwilling to look me in the eye or to speak in more than a matter of a few syllables in any of our first three sessions. Interviews were conducted in his bedroom, the only private place in a communal house, where the walls were covered with pictures of tennis stars and naked women. The only seat was the bed; neither of us was comfortable. Yet he kept appointments and was always first to the phone in the communal house when I rang at pre-arranged times. It seemed worth persevering. On our fourth meeting he was much more forthcoming, giving me a very moving account of the need for someone in his position to do what he thought was right, whatever other people might think or say about him. Later readings have proven the data he has supplied as indeed very rich when taken overall.

In my discussions with others about the study, several nurses asked with concern about the process of termination, and how I would end my relationship with the participants. Taking what was perhaps a default position, I effectively let the participants themselves decide how this should happen. At the end of a series of interviews (usually between five and seven) I told each participant that I had come to the end of the questions I had, and that I did not need to visit any more to interview for the purpose of the research. All concurred, although several continued to contact me intermittently for a few weeks or even months thereafter. They phoned, for example, to tell me to watch a documentary on TV, or wrote to tell me of something significant which had happened in their lives and in which they thought I might be interested. I have no reason to think that this process of termination has not been successful. For a variety of reasons I occasionally see some of the participants in another capacity and am satisfied that we have dealt well with finishing the process of data collection.

## DATA ANALYSIS

In a phenomenological study data analysis consists of phenomenological reflection and of writing and rewriting. The researcher aims to gain a reflective grasp of the essential meaning of the experience being studied and then to communicate this through the written word (van Manen, 1990). Through reading and rereading the text of transcribed interviews, and through examining other sources of data (the other written material which had been given me by participants and others, along with news reports, films and artwork) I endeavoured to grasp the essential, phenomenal structure of the lived meaning of Being-in-the-world with a schizophrenic illness.

The process of data analysis is not an easy one to explain in a phenomenological study. This is partly because the steps of the process are not ordered in a tidy sequence (Madjar, 1991), but also because the process is neither mechanical nor unambiguous (van Manen, 1990). While it is common to read of researchers identifying themes in the data, the process is not a straightforward one such as is found in some types of content analysis. As van Manen explains, there is a considerable degree of insight, intuition and creativity in the search for phenomenological themes. The search is for the meaning of the lived experience under investigation, and for the words with which to describe it and to communicate this reflectively grasped meaning to the reader.

> Making something of a text or of a lived experience by interpreting its meaning is more accurately a process of insightful invention, discovery or disclosure - grasping and formulating a thematic understanding is not a rule-bound process but a free act of "seeing" meaning.
>
> (Van Manen, 1990, p. 79)

The chief sources of data for this study were transcribed interviews (and the tapes from which these were made) along with fieldnotes made during the course of data collection. Written material given to me by participants, news clippings, and so on were used as supplementary data sources and proved particularly useful in stimulating the dialogue with the primary data which is characteristic of phenomenological analysis (Benner, 1985). Interpretation began early in the study and developed as the interviews progressed rather than being conducted entirely independently of interviewing.

As interviews were completed I listened to each tape several times in order to familiarise myself with what had been said at the previous meeting, and to check what questions needed to be followed up and whether I could identify any assumptions I held about their meaning which I felt needed clarification. At this stage I began to develop tentative emerging themes which were later discussed, usually at the last interview with each participant. Van Manen (1990, p. 98) suggests that the conversational interview is particularly appropriate to the task of reflecting on themes of the phenomenon under study because of its collaborative nature. The process was also aided by the participants' interest in hearing of the experiences of others in the study and whether their experiences were similar. While I avoided answering this question directly as I did not yet feel I had a suitable answer, I did find it provided an opportunity to ask about aspects of experience which had been mentioned by one participant and not another (for example some participants mentioned difficulty concentrating and this was an open opportunity to check with others whether this was also something they had experienced).

Listening to the interview tapes and reading and rereading transcripts also alerted me to the context of the lives of the research participants. For example, as participants spoke of their experiences of stigma and prejudice and the discomfort this caused them, my awareness of news reports, TV programmes, and people's casual comments was heightened. In this way I came to grasp something of stigma in the way it is lived rather than its meaning as a concept distanced from personal experience.

At the conclusion of the data collection phase I spent several weeks immersed in the data, reading and rereading the interview transcripts. Here my aim was to grasp the essential structure of the experience of Being-in-the-world with a schizophrenic illness, and to do this by discovering what it was that the participants had said about their experience. In phenomenology this is not a matter of a one-to-one correspondence. Since phenomena are usually covered up, the process of interpretation is aimed at revealing what is being said from what is talked about, in order to illuminate it in a new way.

> Speech "lets us see," from itself ... what is being talked about. In speech (*apophansis*), insofar as it is genuine, *what* is said should be derived *from* what is being talked about. In this way spoken communication, in what it says, makes manifest what it is talking about and thus makes it accessible to another.
>
> (Heidegger, 1962/1977, p. 80)

I first read the series of transcripts from each participant several times, writing a brief summary of what I believed were the main themes of that person's account of life with schizophrenia. Next I began to compare the accounts of participants with each other, looking for similarities and differences, and for the essential aspects of the experience which were common to each account. This is consistent with Benner's (1985, p. 9) suggestion that "whole cases can be compared to other whole cases" and resulted in another list of emerging themes. At this point I also used van Manen's (1990) approach of taking the four lifeworld existentials: lived space, lived time, lived body and lived human relation, as guides to the reflective process, taking each interview in turn and looking for references to each of these existential themes, and including under each heading a series of subthemes. Comparison of these themes across interviews and cases in process of comparing parts and whole (Benner, 1985, van Manen, 1990) resulted in my generation of another organisation of themes from which the text could be created.

## PRESENTATION OF FINDINGS

The need to write and rewrite as part of the process of phenomenological reflection has already been discussed. In this study I have chosen to present the phenomenological account of the lived experience of schizophrenia alongside aspects of Heidegger's philosophical writing in his (1927/1962) work, "Being and Time." The account is organised into four chapters dealing with *Being-in-the-world*, *Being-with-others*, *living carefully* and *taking a stand on life*, each of which is based around concepts central to Heidegger's philosophical discussion in "Being and Time." Within each chapter the data and my interpretive comments are set exegetically alongside Heidegger's concepts (van Manen 1990, p. 171). The reason for this arrangement was not that Heidegger's ideas directed the study, but rather a growing awareness during the process of data analysis and early writing of how good the fit was between the reported experience of the participants and Heidegger's philosophical writing. My purpose in these chapters is to discuss themes arising from the data in light of some of Heidegger's major philosophical concepts. The complexity of Heidegger's thought and writing has made this a challenging project. Rather than the strategy of presenting interpretations of Heidegger's work and then using the data to illustrate the concepts I have endeavoured to present the data as primary and to use Heidegger's ideas in the discussion related to the data, where this is appropriate.

Extracts from interviews have been used throughout the data chapters to illustrate aspects of the experience of schizophrenia as it was described by the participants, and in order that the account remains close to the original data. This process serves both to provide a vicarious experience for the reader (Sandelowski, 1994), and to aid the reader's participation in consensual validation of the research (Madjar, 1991).

The four data chapters which follow address different aspects of the experience of living with schizophrenia. Chapter Four deals with the personal bodily, mental and emotional experiences which result from schizophrenic illness and its treatment and the way these impact on people's experience of Being-in-the-world. In Chapter Five the relationships of those with schizophrenia to others, both in a personal sense and as a part of the wider society, are discussed, while Chapters Six and Seven present a discussion of the care that those with schizophrenia take with themselves, the ways they deal with their past experiences and their future aspirations, and the choices and everyday actions which comprise their comportment in the world in creating lives which are meaningful. Chapter Eight entails discussion of the implications of the study for nursing practice, while Chapter Nine concludes the thesis with a review and suggestions for future research.

## REVIEW AND SUMMARY

In this chapter I have described the use of Heideggerian hermeneutical phenomenology as an appropriate method by which to grasp a better understanding of what it means to live with schizophrenia. The method is argued to be appropriate for the question asked in this study and for inquiry which takes a nursing perspective. The procedures by which the study were carried out have been detailed, ethical considerations identified and an overview of the study participants presented.

No claim is made in phenomenological research that the description and interpretation presented is the only possible one, or that it remains "true" for all time. While I am convinced that the portrayal presented in this thesis accurately reflects the experiences of the study participants, it is important that readers are able to, and in fact do, follow my decision trial (Sandelowski, 1986) in order to make their own judgements about the argument presented here.

# CHAPTER FOUR

# BEING-IN-THE-WORLD

## Introduction

In this, the first of four chapters in which the study findings are presented, discussion is focused on the way in which the study participants found themselves **thrown** into existence, that is to say as who and what they are, and on the ways in which their illness and treatment impacted on their experience of Being-in-the-world. In their stories the participants demonstrate the importance of historicity; their existence in terms of the history of their own lives and in terms of the social system in which they find themselves. Heidegger suggests that Dasein *is* its past, in that "its concrete projects and goals are always appropriated from its historical culture and are always projected along the guide rails that have been laid out by the past" (Guignon, 1984, p. 335).

While the discussion in this chapter centres on the participants' Being-in-the-world in terms of their personal bodily, mental and emotional experiences, it is recognised that Being-in-the-world also encompasses several other dimensions. In the next chapter the experience of the participants in Being-with-others is explored, and in Chapter Six the meaning of Being-in-the-world and of Being-with-others is discussed in relation to the choices participants must make and the concerns they express in living their lives. In Chapter Seven the actions, choices and concerns of the participants are discussed in light of the stand they take on their lives. Chapter Eight serves to present a summary and discussion which integrates the data related to the participants' experience of Being-in-the-world with a schizophrenic illness and identifies the meaning of the study for nursing practice.

The everyday concerns of a group of people with a particular illness experience were the subject of this study. Such concerns are always embedded in what it means to be *worldly*. The centrality of our being-in-the-world is exhibited, and yet often overlooked, in the activities and concerns of this inhabiting (Steiner 1978). They consist, says Steiner (1978, p. 83) in his interpretation of Heidegger's "Being and Time," "of having to do with something, making use of something, giving up something and letting it go, undertaking, accomplishing, evincing, interrogating, considering, discussing, determining and knowing something."

Both illness and treatment have significant effects on one's Being-in-the-world. The study participants incorporated the experiences of their schizophrenic illness and its subsequent and ongoing treatment into their sense of self. Such experiences, which were described in both bodily and psychical domains, were part of what it meant for the participants to Be-in-the-world. The effects of illness and treatment are a part of the lives of the participants, part of their history and their projected future, yet they sit alongside, rather than taking over, other life problems, ambitions, relationships and so on, which are ongoing parts of life as well. Being-in-the-world for these participants encompasses illness and treatment as an integral part of their existence.

In this chapter the data are discussed in light of several themes; **realising that one is unwell, reconceptualising one's Being-in-the-world**, and a series of themes which are connected to the effects of illness and treatment; **hallucinating, feelings of unfamiliarity amongst things in the world, being occupied with one's thoughts, the altered body, accepting the need to take regular medication**, and **coming face to face with the mind-body question.**

## Realising That One Is Unwell

Although the experience of becoming ill was acknowledged by most participants as a major event, it was at the same time not easily accepted, diagnosed, communicated or understood. Throughout the period of data collection one of the participants, Judith, continued to express ambivalence about the diagnosis of schizophrenia as a reason for her problems. As will be illustrated, she had other ideas as to the cause of some disturbing events in her life. Another participant, Adrian, was firm in his statement that he does not have schizophrenia as such, but rather acknowledges one or two symptoms consistent with the illness.

It is not a simple matter to acquire a diagnosis of schizophrenic illness. The problem of diagnosis stems not only from the reluctance of health professionals to name the illness until after a reasonable time has elapsed (DSM-III-R requires at least six months of continuous signs of illness prior to diagnosis) but also from the insidious nature of many of the symptoms of the illness itself. Symptoms such as tiredness, or difficulty with maintaining a job, described as early symptoms by Michael and Adrian are attributable to many other possible causes, some quite outside the realm of medicine. There is also an expressed difficulty for people who are becoming ill, and sometimes those around them, to believe that there is anything wrong.

As Liz explains, in the normal course of life people doubt neither the evidence of their senses nor their own beliefs. Benner and Wrubel (1989) refer to the nature of embodied intelligence and the habitual actions which form our taken-for-granted ways of Being-in-the-world. "When embodied intelligence is working well, it is rapid, nonconscious, and nonreflective" (p. 43). As involved participants, we act in most situations in a nonreflective way. It is only when something goes wrong with the taken-for-granted that we reflect on a situation consciously, realising that something is not quite what it had first seemed. Until this breakdown of the taken-for-granted occurs, we act in any situation without consciously weighing it up or examining it; things are assumed to be meaningful and orderly. Only the person in the situation can make such a judgement about the nature of reality and meaning. When she was acutely ill, Liz believed that she was clairvoyant and that she had discovered some connection between the Russians and the weather. In spite of what sound to an outsider like most unusual thoughts, Liz carried on with her life as she always had:

> *It felt pretty normal actually. Although it was .... it wasn't normal at all. But .... when I had no insight ..//.. you don't doubt yourself, you know, ..//.. you don't sort of think oh, you know .... well you don't have any doubts about, well I try not to anyway, ..//.. you make a decision and you think..//.. or you think about something and you come up with the answer and you don't .... you don't think oh, you know, I could be wrong, you know, and get all stressed out about it, you sort of stick to your decision and go about your business, you know. And that's what it's like, you know, you just make up your mind, I mean however bizarre it is, you know, and just go about doing something about it. So that's .... feels pretty normal. Sounds strange eh?*
>
> (Liz 4, p. 4)

As Liz describes it, she found a way to normalise the unreal, to make her unusual sensations ordinary and to act on them as if they were. Although in retrospect she recognises these thoughts as symptomatic of her psychotic illness, at the time she did not doubt her perceptions or the reasoning which explained them.

Liz suggested that her friends thought it somewhat strange that she hid from people when she was first becoming ill, but explained that they were busy with their own lives and knew little about schizophrenia. They thought it was a phase she was going through, or that perhaps the people she was hiding from had done something to her. Later Liz lived in a supervised hostel with other ex-psychiatric patients, where she said, when she again became unwell people just ignored it; *"Well, because they were sick themselves"* (Liz 1, p. 4). Judith told her parents that she was hearing voices but says they really did not accept this. In contrast Michael's friends were aware that something was wrong considerably earlier than he was:

> *Then the two chaps I was travelling around with in Europe they found that I was very slow. In my actions and speech and everything. And they always used to have me on about it. And I could never understand why they used to have me on about it all the time because as far as I was concerned I was keeping up with them. But they could see differently you know and that was one of the things that really stood out you know, and but at that stage I never realised there was anything wrong with me.*
>
> (Michael 1, p. 2)

Chris expressed concern at the way in which social welfare benefits may enable people who are seriously ill to "disappear" in our society, in circumstances that may be desperate, yet which are away from the public eye. Keeping to oneself may be one way to avoid treatment, which as Chris explains, can be very frightening to contemplate.

> *.... when you have a system where you're bankrolled, but on the dole and stuff, um .... like my illness wasn't diagnosed because I was able to stay on the dole for all those years and I was in hell, I was in a living hell. I was ill. But I could collect the dole and live in a private hotel, not speak to anyone, everyone*

> *was saying go to a hospital, go to hospital; I wasn't going to go to a hospital unless I was forced because I'd seen "One Flew Over The Cuckoo's Nest" and I'd seen it through certain eyes. And I just thought it was a nightmare. I just identified with Jack Nicholson. I saw it again after I'd been in hospital and I identified with the nurse.* (Laughs.) *Nurse RatShit.*[1] *I could see it. I thought what a marvellous person she is.*
>
> (Chris 2, p. 20)

The symptoms of illness itself may also lead to a fear of treatment, as Judith describes below:

> *The first time I went up to (hospital) I was sure that I was being watched in the hospital. So I thought people were watching me, things like that. And I said to David* [partner] *"I'm not safe." That's how it made you feel, like you weren't safe around anybody.*
>
> (Judith 2, p. 6)

The normal way of Being-in-the-world of each of these people was under challenge. Liz had strange new powers of clairvoyance which required contemplation and action. Judith heard voices which disturbed her yet which her parents were dubious about, and she felt frightened everywhere she was, even when presenting for the help she later realised she needed. Michael was puzzled by the reaction of his friends who appeared, in his view, to be unfairly intolerant of his actions and manner. Chris was, as he said *"in a living hell,"* yet his understanding of a popular film of the time left him in very real, felt fear of seeking or being sent for treatment. While he later laughs at his interpretation, it was his experience at the time, a reflection of the world into which he had been thrown. Each of these people conveys their certainty about their thoughts, behaviour and judgement in the face of experiences which sound unusual and in some instances very doubtful to anyone else. At the time they had no reason, as they saw it, to doubt their own judgement.

---

[1] Chris has made an intentional pun here. The nurse's name in the book and film is Nurse Ratched.

## Reconceptualising One's Being-in-the-World

The recognition that they were unwell and required treatment, however slowly it dawned, led each of the participants to reconceptualise their Being-in-the-world. Previous explanations for perceptions, actions and the cause of unusual experiences had to be overturned.

Michael, Chris, Roger and Jack all believed that they had been sick since a very early age. Such beliefs might be interpreted as suggesting that they had been-this-way-in-the-world for as long as they could remember. Since this was the way they had always been, or so they believed, it was difficult for them to accept that they were unwell. Another reason for participants not thinking they were unwell was that there were other ways of explaining "different" ideas, beliefs and behaviours. Chris succinctly describes the role of changing fashion in ideas as contributing to his inability to acknowledge a problem:

> *I think of it as me being sick from the day I was born really.*
>
> (Do you know a lot of people have told me that. But you just didn't know till later?)
>
> *No. .... Because there are all sorts of other things are* [sic] *mixed up in it, there are current political ideas and fashions that fit in with your illness so you think that's .... you grasp those and you don't think I'm being ill, you think I'm being fashionable.* (Laughs)
>
> (Chris 3, p. 8)

Things were a little different for Judith and Liz who both acknowledged the regular and heavy use of street drugs such as marijuana and hash oil and felt that this had possibly been the precipitating cause of their illness. In addition, Judith was quite involved in studying the zodiac, tarot cards and other occult practices and was uncertain about dismissing the power of the spirit world in having something to do with her problems. Judith had also had an accident not long before her diagnosis, and attributed some of the symptoms of her illness to a head injury she believes she sustained at the time.

> (Can you remember when they first told you that you had schizophrenia? Can you remember what they said to you?)
>
> *Probably when I went up to (hospital). ..//.. Jane* [community health worker] *mentioned it to me. I thought I had contact with the spirit world, eh? That's what I thought. Drawn from the community. But they said it's not that, it's an illness that you've had. And I thought that's pretty strange, I'd gone into all these books and found these various things and I was pretty confused myself. I wasn't sure whether it was or whether it wasn't. I think having something to do with the drug scene that that made it happen too.*
>
> (Judith 2, p. 4)

Whatever the cause of the illness, coming to terms with it *as an illness,* and reconceptualising one's Being-in-the-world in this light was a gradual process, with weighty consequences. Some of the problems which arose for participants stemmed from having to deal with the prejudices of others once their way of Being-in-the-world had been given a name. This aspect of living with schizophrenia is discussed in Chapter Five. Other consequences arose from treatment and its effects on the body as well as on the mind. These, and the effects of internalising, **in-corporating**, an image of one's self as one with schizophrenia will be detailed as the discussion progresses in this and the following data chapters, but discussion turns first to some more specific effects of the illness itself on the experience of Being-in-the-world.

## Illness, Treatment and Being-in-the-World

Both illness and treatment affect the whole of one's Being. Although schizophrenia is thought of as primarily a mental illness, in fact it has major effects on the body as it is lived, as do hospitalisation, drugs and other therapies such as ECT.[2] There is no way to separate, for instance, the sensation of hearing voices from the experience of hearing, visual hallucinations from the experience of sight, or tiredness or fear from an experience of body, mind and spirit together.

---

[2] ECT. Electroconvulsive therapy, known colloquially as "shock treatment."

One *hears* voices, *sees* things, *feels* tired, anxious, restless or afraid. Each of these symptoms is an experience which affects Being-in-the-world as a whole.

In this study there were differences between participants as to which symptoms bothered them most. No two had identical symptoms although several were described in very similar ways. Since all the participants were taking medication it would be difficult to determine in any objective way which symptoms and experiences were related to illness and which to treatment, and to what degree. Although on the whole the participants were clear which was which (as will be shown in the examples which follow) in a phenomenological study such as this the distinction is not critically important. Having the illness meant that all participants took regular medication. Both the illness and its treatment had, at the time of the study, become part of Being-in-the-world for each of the participants.

### Hallucinating

Hallucinations, perceptions for which there are no external stimuli, are a common symptom of schizophrenic illness and were described in vivid detail by those participants who had experienced them. Hallucinations may involve any of the senses. In the following cases they were auditory, visual or tactile. Of whatever type, they had powerful effects on the person experiencing them. If attention is turned toward the experience as it is lived by the person, hallucinations cannot be interpreted simply as mental or perceptual phenomena. They are experienced as affecting the whole of a person's Being-in-the-world.

Lucy suffered from frightening hallucinations when she was most unwell, and as she explains, still occasionally experiences some of these sensations. She begins by describing how real the voices sound, her statement reinforcing Liz's earlier explanation of not doubting what she heard.

> *Because they're so normal sounding, well it's not normal .... but because they're so clear and coherent you think well .... sometimes you get embarrassed because you think cor, everybody's listening to that. And why isn't anybody going red, you know, things like that. Sometimes they do it now and it's just a silly little kind of thing. 'Cos I probably get visions worse*

> *than voices now. But it's in a very obscure way like in trees and like I used to, when I used to walk to the dairy or just up the road, I'd have a thing about rats. I'd stand on rats, you know, things like that. And you can feel them squish between your toes. So then I'd never walk barefeet* [sic] *for years because I'd think shit, I'm going to stand on another bloody rat. And I went to the dairy one day and the rats were in my long hair. And I said "I'm not going to that dairy." So I looked in the mirror and they were all crawling and creeping and they had those long tails and they had like blood between their teeth and it was disgusting. And I thought if I go into that dairy she's going to think what am I doing putting bloody rats in my hair just to scare her or something. So I had to turn back halfway. And worms. I can't walk at night when its been raining. I still can't do it now because I don't like killing animals. Snails. And eating stones, chewing on stones when I'm eating my porridge or something. I can chew, chew, chew like I'm stepping on snails but in my mouth. Some things have stayed behind.*
>
> (Lucy, 1, p. 15)

Jack does not hear voices but there are times when he experiences strange visual images:

> (What happens while you're hallucinating? What sort of things?)
>
> *Oh just jagged yellow lines, all queer and then me* [sic] *brain goes .... part of me brain wants to go to sleep and part of it's frightened to go to sleep. It's horrible and I get horrible bizarre fantastic horrible pictures in me brain but I usually get to sleep sooner or later and then sleep it off.*
>
> (Jack 2, p. 23)

Jack sleeps off his unpleasant hallucinatory experiences whereas Lucy, in the past, has resorted to some extreme physical acts in an attempt to stop her hallucinations. In the following passage she explains some of the methods she has called on in attempts to rid herself of her voices:

> *But I've tried lots of things. I thought about cutting my long hair, that that would release them. And growing my eyebrows back, because plucking them might have made them more severe. So I just grow them and now they're big ..//.. eyebrows. And I thought by doing this,* (demonstrates picking at skin on her hands) *..//.. see they've gotten a lot better, I thought by bleeding and cutting .... 'cos I can sit in front of somebody and just get a knife, I can still do it now, but not a knife, and I would just pick pick pick pick pick pick, and I can rip like about a centimetre deep of skin off.*
>
> (Lucy 1, p. 15)

Whether hallucinations are pleasant or distressing, when they cease they may be missed, as both Lucy and Liz explained. Liz noted that she had not realised that "normal" people (a term she herself used) did not hear voices in the way she did. Lucy became quite depressed when her voices first left, and admitted that, horrible as they had been, she felt lonely and alone without them. Later, however, she was able to see the benefit of having time to herself and being free to listen to what she chose.

> *It took a while to listen to everything they said, but when I did absolutely everything they said it was when I couldn't go to class. I had to leave school early. I just loved being with them and me. And it's so quiet without them, but it's lovely because I can do my own things. And I mean I can listen to a walkman now. I haven't been able to do that since I was fifteen.*
>
> (Lucy 2, p. 21)

While Lucy claimed to enjoy Being-with-her-voices at this period in her life, their influence over her was strong enough that at another time she carried out some elaborate plans laid down by the voices and very nearly succeeded in committing suicide under their instruction as to how to overdose.

The hallucinatory experience which (as has been emphasised) is not simply one of hallucinating but rather of *hearing*, *seeing* or *feeling* frequently interferes with other activities, as Lucy explained, and may also make the conduct of activities which are usually taken for granted very taxing, if not impossible.

> *And then a friend, ..//.. he's an artist, he picked me up one morning when I didn't go to work and I was just walking the streets of (town) when I was living there, he took me to his place. And I couldn't, I couldn't, .... I didn't know what he was saying. I could see his mouth move but I couldn't actually hear what he was saying because I was so, ....* [the voices were] *blabbing so loud. But I never hear voices inside my head. It's around me. And when I'm hearing eight at a time and somebody's trying to talk to me you can imagine how confusing that is. ..//.. Because you're listening to that one, that one, that one, that one, that one, and then you've got to listen to the person who's actually in front of you.*
>
> (Lucy 1, p. 19)

Hallucinations are a well recognised symptom of schizophrenic illness. Other less well known perceptual changes may precede or accompany a psychotic episode, or occur at other times, as participants describe in the following section.

### Feelings of Unfamiliarity Amongst Things in the World

Several of the study participants reported episodes of feelings of unreality or strangeness. These feelings were difficult for the participants to explain but appear to correspond closely to the notion of unreality which precedes an acute psychotic episode, described by Sass (1992a) and postulated by him to run a close parallel with the work of some of the modernist artists and writers (Sass's work was referred to in Chapter Two, pp. 65-66). The feelings of unreality described by the study participants also closely fit the concept of *uncanniness* described by Heidegger (1927/1962), and can be analysed in terms of his notions of the breakdown of the *ready-to-hand*.

Both concepts; uncanniness and the breakdown of the ready-to-hand will be elaborated after an example is quoted from the data. In this lengthy quote Jack attempts to describe to me what these feelings of unreality are like:

*What else can I tell you? .... Ask some questions about .... about schizophrenia. Oh I get feelings of unreality occasionally. Not occasionally, rarely, but I do get them. Do you know what that means?*

(Tell me what it means.)

*Well it's different, that's only way I can sum it up. You know I might go .... I had it the other day after he changed me* [sic] *pills. Dr Gerard. ... I went down to (hospital) and I had a different mental impression, in the .... in me brain, to what I normally did. That was just walking in there. Things seemed, not actually different, yeah sort of different, I don't mean the furniture was different but .... I felt differently about it. And you know you get feelings .... unreality to what you normally get. Different to what you normally get.*

(It looks different, or it ....)

*Well it doesn't look different, no ....*

(It feels different?)

*Well .... I feel different about it. Yeah it seems .... it seems sort of different to me, I have a different outlook about it, that sort of thing, you know. You get sort of feelings of unreality it .... it can be .... if it's strong it's disturbing and worrying. It worries you a bit. You feel unsure of yourself. That's the way to sum it up, you feel unsure of yourself. I have heard it referred to as unreality and inreality and that but ah .... it's just different. That's one of the things.*

(They're quite difficult to describe some of these symptoms, aren't they?)

*Mmmm. Well you've got to liken it to something that you'll understand. You see if you've never had a total nervous breakdown you <u>really</u> don't know what it's like. You just don't*

> *.... I can't put it into words to liken it to anything that will mean anything to you you see. But you've got nothing to .... you've got no .... see, ah ....* (demonstrates how cup sits on saucer) *this is a cup because this is a saucer. You've got .... if this was the only thing in the world well it wouldn't have the same meaning to you because it's got a saucer, cup and a saucer; you can compare. And if I explain to you you've got to be able to compare it to something that you know, understand and .... and if you've never been through it it's difficult to do that.*
>
> (Jack 2, p. 20-21)

Heidegger (1927/1962) describes a feeling of uncanniness, which he explains also may be conceived of as *not-being-at-home.* In a state of anxiety one feels uncanny. It is a state in which "everyday familiarity collapses" (Heidegger 1927/1962, p. 233). Anxiety in Heidegger's definition is a more complex state of mind than that which we take it to be in common usage. He suggests that we become anxious not about this thing or that thing, but rather in the face of Being-in-the-world as such. Things, particularly objects which may be used toward some end, are *ready-to-hand* when they are employed smoothly in practical activity. In those moments when we realise just how things are in the world, as separate from us, when there is nothing ready-to-hand, then we are anxious. In the passage above Jack describes, with some difficulty, how things became different *to* him. Their common, smooth functioning broke down and he was left puzzled and uncertain; unsure of *himself* in his relation to the things around him.

Jack remembered another, similar, experience involving his relation to things and people. The difficulty he has in finding words at the beginning of his description reflects the disturbing and strange experience this was for him.

> *So I've been in the state of total mental dep .... intellectual .... when people .... Well just before I came out of (hospital) they had me delivering the mail. And I didn't know what I was doing. I know the letters went all .... I probably lost half of them. I remember .... I do remember a few words. I remember one of the girls there saying to one of the blokes that was in charge of the office "I don't think he knows what he's doing." And he said "Let him persevere." But some of the words they*

> *spoke there was no intellectual acknowledgement in me* [sic] *brain.*
>
> (The words didn't mean anything.)
>
> *Yeah me brain was intellectually numb.*
>
> (Jack 2, p. 22)

Experiences such as those Jack describes are not easily articulated, and are difficult for those who have not undergone them to imagine. However, they clearly have an impact on the person whose perspective, relationships with the things about him and whole Being-in-the-world has been altered by such an experience.

Sass (1992a, p. 45) writes of the perceptual and emotional experiences which accompany states such as Jack describes above and suggests that they can give rise to "the sense of radical alienness that some European psychiatrists have considered the best diagnostic indicator of schizophrenia."

> To patients in this state of mind, the world is stripped of its usual meanings and sense of coherence and it therefore defies any standard description. Everything bristles with a new and overwhelming quality of definiteness and significance, yet patients cannot say what the special meanings they sense are, nor just what is important about the details that, in their ineffable specificity, so compel their attention. Even the most articulate schizophrenics are usually reduced to helplessly repeating the same, horribly inadequate phrase: everything is strange, or everything is somehow different.
>
> (Sass, 1992a, pp. 45-46)

A different kind of breakdown between body and world is described by Michael who sometimes does maintenance work around his house but can find that his coordination is poor and that he has trouble with the tools he is using. This problem, which he conceptualised as one of poor coordination resulting from confused thinking, is another good demonstration of the unexpected unreadiness-to-hand of tools. In the ready-to-hand state Michael's building proceeds smoothly, but at times he and the instruments are somehow "out of synch," the habitual smooth activity suddenly becomes derailed.

> (You're practical?)
>
> *Oh yeah well being a carpenter you have to be. But I'm not very good on the tools though. I think my coordination is controlled by my thinking. That's getting back to this confusion bit where my mind gets confused, where I'm building something or .... um .... I get a bit confused and sidetracked and it means I'm not working my hands properly, controlling my tools properly. So things don't quite go right as .... I never have been a very good carpenter actually. In theory it's all right I can do the theory of it all right but as far as handling the tools go I'm not very good at times.*
>
> (Michael 4, p. 10)

Michael's account contains a clear description of the breakdown of smooth non-reflective action. In such a state the body becomes aware of itself rather than simply being absorbed in practical activity. Indeed Michael's consciousness of his difficulty with carpentry tools is very similar to Heidegger's classic description of the breakdown of the ready-to-hand in which he uses the example of equipment such as a hammer. As Heidegger describes it, things are ready-to-hand when we are engaged in smooth, everyday action as, for instance, in hammering. When things are going smoothly we concentrate on the work rather than the tools, the latter being taken for granted as an extension of our actions in the world. When something goes wrong, however, and smooth functioning breaks down, we become aware of the hammer as a tool, separate from us. It suddenly becomes conspicuous and we see it as "an equipmental Thing" (Heidegger, 1927/1962, p. 103).

In Michael's case, it is not only the tools of which he becomes aware, but his own bodily functioning and his ability to coerce it into the smooth actions he plans and imagines. Participants in the study described not only the way in which they were aware of their bodily actions, but the way in which they might also become aware of their thoughts, which sometimes became overpowering and distracting.

### Being Occupied With One's Thoughts

Nearly all the study participants spoke of difficulties which arose for them in their everyday life as a result of a mind busy with thoughts. Sometimes this was simply a matter of having trouble concentrating; it was often possible to detect a participant's mind wandering off during interview sessions, and most participants said that they frequently experienced several thoughts at once. Many said that it was difficult to read for this reason, and interviews were quite tiring for several participants because of the effort they had to put in to concentrating. More distressing were persistent unhappy thoughts. Such thoughts might be explained and labelled as confusion, worry, anxiety or fear and often took up considerable amounts of time for those who experienced them.

Chris reported lying in bed every night contemplating his life and whether he was yet ready for suicide. Judith spent a lot of time considering the nature of her illness and dwelling with ideas that there was some conspiracy involved. Roger said he felt "*anxiety toward life in general*'" (Roger 3, p. 2). Michael and Jack expressed more pragmatic concerns. Michael talked of his confusion, emphasising his difficulty at the end of this interchange, perhaps in order to make sure I did not minimise his experience.

> *Oh, not being able to think straight at times, um .... like, um .... trying to solve a problem, or um. .... solve a situation, and you get all confused and, you end up not knowing what to do and .... but after a while you, .... after a period of time, suddenly realise what you should have done, and what you shouldn't have done, and .... I suppose it happens to the normal people though, doesn't it?*
>
> (Yeah, I'm sure.)
>
> *But in schizophrenic people, its a lot worse, they get confused, and can't think straight.*
>
> (Michael 6, p. 8)

Even very simple, everyday tasks can become overshadowed by a mind which is busy with worrying thoughts, until the work itself becomes an impossible task.

> *Well what I normally used to do, and love, worries me now, I don't do it. I try and do it .... I've got to drive meself to do certain things at times. Force meself* [sic]. *For instance when I'm gardening I don't garden for an hour. I'll go out for ten minutes, come inside, have a cup of tea and a smoke .... for ten minutes and then go out and do another ten minutes. I can't stick at it all day. I used to work. .... I worked for five years in the council and ah .... I was there every day except when I went fishing, I took days off to go fishing. You know the whitebait season opened, I was away on opening day and things like that. I used to get time off. But I drove meself for five years until I became a leading hand in charge of the (job) and so .... I could .... I could do it then but I .... as I say I get that way I can't even wash the dishes some nights.*
>
> (Jack 2, p. 20)

In this description of his interrupted action Jack talks of being worried by the things he normally used to do and love. Worrying was something Jack claimed to be an expert at, suggesting to me that anything I could think of, he could worry about. His returning to the house to smoke and drink tea was also an occasion to let his thoughts roam and to do some worrying, as he explained it. The connection between thinking and physical inaction has parallels in other participants' descriptions of the effect of their illness on the body.

### The Altered Body

One of the strongest themes to emerge from the data related to bodily changes experienced by the participants as a result both of their illness and of its treatment. As was suggested earlier, although schizophrenia is usually thought of as a *mental* illness, it incorporates a number of *physical* aspects. As it is lived, schizophrenia is experienced not just in terms of its cognitive manifestations, but bodily. While it is in some ways self evident that human beings are bodily in the world, it is nonetheless sometimes easy for health professionals to overlook physical ramifications of mental ill-health, or to minimise their significance when such problems are not connected to primary symptoms of illness. We know that it is the body which is treated with medications and that some of the more severe side effects of drugs are physical, yet we may forget the everyday implications of illness in terms of physical well-being and people's ability to undertake usual activities. The physical problems which arise as a result of illness and treatment are arguably more troubling for people, such as those in this study, who are ostensibly well, than are the perhaps more intense physical reactions which may be monitored during a period of acute illness and treatment. The "well" must cope with physical symptoms that are ongoing and often quite disabling, yet there is little that health professionals can do to alleviate them, even when they are recognised.

The classification of the symptoms of schizophrenia into positive and negative as is found in textbook descriptions does not parallel the experience of people with the illness. For example, tiredness is not only experienced as a lack of energy, as something missing or absent; there are aspects of the experience of tiredness which are experienced as attributable to the *presence* of bodily sensations such as heavy limbs and slowed movement and thinking. There is another problem which arises in relation to the terms used to define the symptoms of illness. One of the commonly recognised "negative" symptoms of schizophrenia is avolition-apathy (included in the majority of negative symptom rating scales discussed by Schooler, 1994). In New Zealand the term "lack of motivation" is in fairly common use and was spoken of by all study participants. The lived experience of the study participants was that this symptom belonged much more to the physical realm than to the psychological. The DSM-III-R describes lack of initiative, interests or energy as a possible prodromal or residual symptom in schizophrenia, thus spanning the physical and psychological realms in one symptom. Several participants in the study described lack of motivation as a feeling of tiredness or as difficulty in commencing or completing tasks, no matter how much they *wanted* to do them. If motivation is taken as a synonym of will, then the difficulty expressed is not really one of motivation but of **propelling the body into the world**.

In the previous extract Jack talked of needing to *force himself* to do things. He himself suggested that the problems he described were due to lack of motivation. Yet he is clearly not lacking in desire; rather he finds it difficult to have his body follow through with the actions he wishes to undertake. Michael describes the difficulty he has getting out of bed in the morning:

> *But for the sufferer, the schizophrenic sufferer, it's quite hard for them to get up out of bed in the morning because they just lack that motivation. They just feel, I don't, .... I don't think they feel tired because they can't sleep, but they just haven't got that get up and go. To a normal person that getting up out of bed in the morning comes quite easy, or nine out of ten people anyway. But for the sufferer it's really hard and they've really got to push themselves to get going.*
>
> (Michael 2, p. 9)

For Michael "lack of motivation" was a persistent problem, and the most troublesome symptom he had to deal with. He felt that he suffered from this problem to an unacceptable degree and that his difficulty in being able to do things because of tiredness (he used the terms tiredness and lack of motivation synonymously) needed some attention. Michael had sought advice from several health professionals yet felt that he was largely unheard and unhelped. Tiredness and the consequent difficulties in propelling the body into the world interfered with the participants' abilities to work, and to engage in recreational activities.

Tiredness and sleepiness are well-recognised side effects of neuroleptic medication and were recognised as such by several of the study participants. Judith found that her medication interfered with her ability to stay awake during the day.

> *Yeah. I always go back to bed after taking Rosie* [daughter] *to school. But I get lazy. I don't know whether it's the Trilafon. I've been like that for quite a while, you know, really. Just always tired in the morning, which is a real pain you know because it takes away half your day. You think I've got to get up, you know, I've got to get up. You know, I've got to get up and stay up. And I can't get up because I'm still tired, you know. It's a real hassle that.*
>
> (Judith 4, p. 20)

Like Judith, Roger found that the sleepiness caused by his medication interfered markedly with his everyday life. He told me that he had asked for a reduction in his medication because his blood felt *"like concrete flowing in my veins."* His doctor had talked of reducing the procyclidine Roger was taking but Roger was not keen to accept this proposal:

> *.... but I said no, I want it. To keep the side-effects away. But with the Haloperidol, I was trying to explain to him, well he knows anyway, but the Haloperidol makes you drowsy, and you can't do anything, you can't even have a bottle of beer without having your brain going funny.*
>
> (Roger 2, p. 1)

While the consumption of alcohol may not seem a very important part of life to some, to be limited in one's capacity to drink at all, given that the need for medication is ongoing, was in fact felt as a burden by several of the study participants. Their care over alcohol and street drug intake was volunteered by several (not all) of the study participants and emphasised as of concern to them. This topic will be discussed again in Chapter Six.

Paradoxically, while tiredness or sleepiness were troublesome for a majority of the study participants at some time, a few were affected by restlessness attributable to their medication. Only one participant, Lucy, actually spoke of feeling restless, but the extensive walking engaged in by Adrian, and addressed in Chapter Six, fitted a picture of restlessness often seen in clinical settings, and two other participants were observed to have apparent difficulty sitting or standing still during interview sessions. Lucy explained that she felt several bursts of energy during the day, one at five in the morning, one at eight at night, and one about eleven at night. *"That's when I really rev up and go. I can't sit still. I can't stay still. I have to make all these toll calls. Clean and clean and clean"* (Lucy 2, p. 3). The picture Lucy gives becomes a little more complicated when it is recognised that she also has a habit of attempting to counteract her medication with large doses of coffee. These, and some other actions designed by others to overcome undesirable side effects of medication will be discussed in more detail in Chapter Six and later revisited in light of the implications they present for nursing practice. At this point it is worth noting that restlessness was not described as a problem by any of the study participants. Although it was observed in small degree in three participants, surmised in Adrian's case, and described by Lucy, none of the participants reported, or *felt,* discomfort or interference in their everyday lives as a result of this recognised side effect of neuroleptic medication.

It is relatively easy to understand and sympathise with expressions of limitations because of tiredness or sleepiness. These are bodily experiences which people who have never had a schizophrenic illness have shared to some degree. Another, not uncommon, side effect of antipsychotic medication is the acute dystonic reaction.[3] While it is easy to appreciate that this reaction must be frightening, the intensity of fear it engenders is known only to those who have experienced it:

> *One of the big things that happened at school was they hadn't started giving me side effect medication, side effect pills. And my eyes turned up. Oh my God, that's the most .... I've had that happen to me so many times when they've stopped giving me them. It's scary. You cannot sleep. You cannot close your eyes because they just blink so much. ..//.. Oh I hate it. I wouldn't wish that upon my worst enemy. Your eyes crept to the ceiling. Oh God. You just can't bring them down. And you can't go to the toilet because you're too scared that you're going to keep looking up.*
>
> (Lucy 1, p. 6)

Other vivid descriptions of bodily experiences related to their illness were given by Lucy and Roger, who both mention the use of a mirror to examine and verify their physical appearance. Lucy's experience is directly related to her illness and subsequent improvement, Roger's to the stress related to a change of doctor and of remembering the times when he had been most unwell.

> *Because I used to avoid looking in a mirror because my eyes popped out of my head and the pupils were really dilated. ..//.. And sometimes I used to look in the mirror and I used to see spiders all over my face. I used to get so scared and it made me feel even more alone looking at my eyes because I was so frightened. And I can look in the mirror now. And sometimes if I'm extra tired then they'll go smaller. And it's just nice. You can look in the mirror and think aah, you're not that gorgeous*

---

[3] An acute dystonic reaction is a side effect of antipschotic medication, characterised by abnormal, sustained, posturing movements of the neck, jaw and eyes. It often involves protrusion of the tongue, spasms of jaw muscles and oculogyric crisis.

> *but, you know, your eyes aren't bulging out of your head. You know?*
>
> (Lucy 1, p. 19)

> *Well, there's been a change in the system again as usual it changes every week. And actually, my ex-doctor has gone to be with community health services* (in another community) *he looks after the acute patients, in a crisis or something. But Dr Phillips* [a doctor Roger had been seen at another hospital] *has been here* [at the local hospital] *for some years actually now. When I was going to him before I, .... funnily enough this time I had a strange night, when I last saw him, because maybe something in my subconscious mind, I woke up at 1.00am and my brain was throbbing like hell, and I went and looked in the mirror, and my eyes were way back in my head, and I thought, shit, this is not too good. And I thought well I'll just remake my bed and get back in again, because my bed was a wreck. Because most of the times I've had contact with Dr Phillips I've been ill. I must be subconscious of him being my doctor again that sort of spooked me.*
>
> (Sort of reminded you of all the bad times.)
>
> *Yeah, all the bad times again, yes, that's right.*
>
> (Roger 2, p. 1)

Because of their illness each of the study participants took medication on a regular basis. Mention has previously been made of the impossibility of any objective separation of illness and treatment in terms of their effect on the whole of any participant's experience (pp. 107-108). Participants in the study were, however, quite clear about many of the effects of medication on their lives, as has been apparent in their descriptions of the bodily effects of drug treatment. Coming to terms with the need to take regular medication was part of living with schizophrenic illness.

### Accepting The Need To Take Regular Medication

Given the unpleasant side effects which were experienced by most of the study participants, it might not have been surprising to have found that they were reluctant to take medication. In fact this was not the case. While some were a little dubious about their need to take medication on a long-term basis, as Jack and Judith illustrate below, the general feeling expressed by all the participants was that medication was a necessity.

> *I still feel that sometimes that there's nothing wrong with me. Because I'm on the drugs I feel as if I'm OK and I don't need them any more. But I guess I do.*
>
> (Judith 1, p. 5)

> (Tell me about the drugs you have to take. How do you feel about taking drugs all the time?)
>
> *Well, I have doubts about them.*
>
> (Doubts about them?)
>
> *Well, they mightn't be worth a tin of fish.*
>
> (That's a polite term.)
>
> *Yeah. They mightn't make any difference to me at all. Probably don't. Oh they might do, or they might do damage, some tranquillisers actually do kill people, people have died through tranquillisers. When they've been prescribed, they have actually died, and they can cause damage. But I do take them, it's prescribed them for me* [sic], *presumably someone's done research somewhere about them, and what have you. I do take them.*
>
> (Jack 5, p. 4)

Most participants reported having carefully considered the consequences of not continuing with medication and felt that on balance, it was better to tolerate troubling side effects than to risk the extreme distress associated with an acute episode of illness. Medication was thus a form of insurance, a way to help themselves stay well. Some were frustrated by the need to continue to take medication which so affects functioning on a daily basis, as Lucy explains:

> *And I just thought, 'cos they always told me that I suffered from depression, so I didn't mind taking these pills. Lots of them, and making me feel really sleepy and making me burn, and I had to wear a hat and sunblock every single day. And the psychiatrist said "You have to wear sunblock. As soon as you get up, put it on." You know, fancy that, having to put bloody sunblock on when you get up in the morning.*
>
> (Lucy 1, p. 21)

Of all the participants, Chris was the one most severely affected by medication side effects, to the extent that he regularly contemplated suicide.

> *Well it's .... it's because of the side effects of the medication. Like I might have told you before it lowers my libido and that's why I want to kill myself. Just takes all the fun out of life. The only thing that makes adult life worthwhile and I no longer function properly at that level.*
>
> (Chris 2, p. 6-7)

While Chris frequently expressed ambivalence about his willingness to continue his medication regime, he did take medication during the course of the study, a fact which indicates a great deal about his determination not to become ill again if he could help it.

There was a general acceptance amongst the participants in the study that their illness was a continuing and long-term one and that while some symptoms persisted, medication had been effective in enabling a return to a "normal" life. Indeed, Simon even felt that he had been able to begin a new life once he had begun neuroleptic medication.

> *I think the time since I was put on anti-psychotic drugs was the beginning of a new life. .... that it was gradually going down-hill over the years through my teenage years. And I think ....*

> *that a lot of the processes of adolescence occurred to me after that. After my .... after the age of twenty-five.*
>
> (Simon 1, p. 3)

Liz had recently asked that her medication not be changed for a year. As she explained, a medication change is a major concern for her, and she felt that she had some stressful times ahead which she would rather handle without also coping with new and different medication. At the same time she expressed her ambivalence about this situation, since she would rather not take medication at all, if that were in any way possible.

> *.... but at the moment for myself, my medication won't be changed for another year .... because I've requested it that way. ..//.. because medication change is quite a dramatic thing for people that are schizophrenic, or anyone with an illness. Because you think you may relapse, or that, you know, that it will have a real effect on you which of course it does.*
>
> *.... no-one wants to take medication unless they have to, so if someone tells you we're lowering it, you're eager to go along with it, you know, you want to try anything really.*
>
> (Liz 4, p. 16)

In accepting their need to continue to take medication the participants are faced with having also to deal with its side effects. In addition, the need to take medication signals that they are in some way different, that although they appear well and wish to move on with their lives, they need protection from the possibility of further acute illness. Taking regular medication becomes a part of their Being-in-the-world.

### Coming Face to Face With the Mind-Body Question

The discussion in this chapter has concentrated largely on the study participants' experience of Being-in-the-world. One of the greatest impacts which the experience of schizophrenic illness has on those who suffer from it is the way in which they find themselves contemplating the connection of mind and body. The process by which the person with schizophrenia comes to doubt his or her experiences and the effect this has on Being-in-the-world has already been introduced and illustrated by Liz's statement that she did not initially doubt her experience of hearing voices, and that for some time she did not know that other people did not hear voices (p. 110). Having come to that realisation, however, she understands that nothing will ever be quite the same again.

> *Because you challenge your whole .... every idea you have you challenge, because you think it could be, well you don't .... at the time you don't think that it could be .... but, as you get more insight, you think that your ideas could be psychotic in some way, or, you know, or that they could be not like what other people are thinking. .... And you tend to question yourself quite a lot.*
>
> (Even when you're well?)
>
> *Oh yeah. But its sort of at a less acute stage so you've got more time to think about it anyway. You're not sort of panicking. Yeah.*
>
> (Liz 4, p. 15)

Several other participants in the study also reflected on the effect that medication had had in changing their thoughts. To discover that one's beliefs might be changed by medication was to be challenged in a most fundamental and disturbing way. If my thoughts are able to be altered through some chemical intervention, then the question follows "Who am I?" Three examples of statements which illustrate participants' concern with this existential question are given below. The extract from Chris comes after his reference to persistent thoughts of suicide. As he explains even these thoughts, which are regular, persistent and feel as if they are part of him*self*, might be made to leave:

> *I'm open enough about it with anyone who wants to know, they keep asking me questions and they find out the same thing that .... and um Diana* [health worker] *said to me well just how real is this? And this was when .... just after these two people died and I said "Oh I think I'm getting really close to it now." But that was months ago and I haven't got anywhere. But maybe Dr Mitchell will be able to change me. Like he's changing my*

> *medication and he might be able to change the way I think because until I had the last talk I had with him I always thought it would be ideal for me to be in a hospital and not on drugs, even if everyone else was not on drugs and they were all running round screaming and things like that I'd rather be like that because I'd be on a high. And he almost convinced me, well he's trying to convince me that even if I was on a high it wouldn't be good. And he's got a lot of knowledge about that sort of thing so I don't know. I'm having to rethink that and if you can make me rethink that you can make me rethink anything.*
>
> (Chris 3, p. 19)

> *No well Dr Phillips has the opinion that .... ah .... you don't think what you think. You say I want to think this and so on but you don't actually do that. It's* ***all*** *automatic. Chemical, electrical. Take a pill and you think differently. Well it actually happens.*
>
> (Jack 2, p. 9)

> *Experiences like that* [the effect of medication in altering thought] *can undermine one's confidence at the most profound level, I think. That you have such a graphic demonstration that one's own mind is a mechanism. Ah .... that beliefs, which should have the validity of beliefs are really .... can be changed by taking medication. That is a very difficult, a very deep thing to come to terms with.*
>
> (Simon 1, p. 3)

Simon later went on to describe the effect that this kind of experience has had on his relationships with others. His experience will be elaborated in this context in Chapter Five.

Two other aspects of the mind-body connection are hinted at in these extracts; the effect of medication in controlling mood, and the location of thoughts and emotions in the brain. Chris, above, spoke of his wish to be taken off medication even if he were then in need of hospitalisation, because he would be "on a high." Although, on the whole, participants would rather take medication than suffer the effects of illness, there was sadness expressed by several participants in that they felt "controlled" by their medication. Drugs had the effect, they said, of limiting their feelings. They no longer felt strong emotions, either of sadness or of joy, and they missed experiencing these feelings. Michael talked of people having "blunted emotions," a term which is used in text book descriptions of schizophrenic illness. He saw this as a part of his illness as a whole, rather than relating it to medication, specifically. Liz attributed her feeling of being controlled to her medication and described her experience in a way which was typical of several of the participants:

> *It's .... it's very confining, like you can never be really happy or really sad, you're just sort of in the middle, well that's how I feel. Really controlled. But .... you know sometimes you just feel like being really happy, but you can't be.*
>
> (Liz 1, p. 5)

To be controlled by medication is **to lose part of oneself.** Not only is a person in this situation faced with the question "Who am I?" if chemical substances can change thoughts and beliefs, but if medication dampens emotions, people feel as if they are unable to express all of themselves. Liz feels she would like to be happy but cannot be. She is unable to experience all she knows she could. She is unable to live up to the possibilities she sees and cannot express herself as fully who she is. In spite of its multiple effects, each participant accepted the "trade-off" as Liz called it, of having to take medication on a long-term basis. The Being-in-the-world of the participants is affected by the chemicals they take in order not to suffer the symptoms of acute illness, while the need and agreement to take medication is at the same time part of their Being-in-the-world.

Given the awareness of the connection between mind and body which has been described, it is not surprising that all of the participants at some stage spoke of schizophrenia as a problem located in the physical brain. Most spoke of schizophrenia as a brain disease or a chemical imbalance, though one participant spoke of having "lost my mind" and one of his brain "snapping." This explanation of schizophrenia as located in the brain fits the experience of the participants and is not necessarily dependent on what the participants have read or been told, although it is compatible with some current theories of the cause of schizophrenia, discussed in Chapter One. The participants actually *experienced* brain problems rather than having learned or theorised that this is the "real" nature of their illness.

Toward the end of the interview series each of the study participants was asked to sum up what it was like for them to live with schizophrenia. The intensity of the experience for each of them, and the effect that this illness has had, and does have, on Being-in-the-world is demonstrated in the three extracts which follow. Lucy spoke mostly about the feelings she had had when acutely ill, while Liz carries her description into the present. Each of these women had **felt dead** during some of their illness. To feel dead while still alive is no longer to be a person at all, to have no place in the world. To feel dead while still alive is to be temporarily suspended in a place of nothingness. The whole of their Being was felt to be obliterated at least for a time. In their descriptions there is a parallel with Chris's statement (p. 104) that he was, for a time, "*in a living hell.*" The disturbing nature of these feelings, along with those explained in the previous section, of experiencing "*one's mind as a mechanism*" are themselves life-changing ones.

In this extract Lucy is describing a self portrait which she completed in hospital:

> *This is just before I got shock treatment. I did this one in hospital. That's me. That's how I looked, honestly. The head and the heart. I never cried, never ever cried once in hospital. I just had no tears. I just felt so dead. And after the voices went I felt even less.*
>
> (Lucy 1, p. 47)
>
> (Could you sum up for me, how having schizophrenia has changed your life?)
>
> *Six months of immobilisation. Yeah, literally, a period of being a dead person, for me anyway of achieving .... well, for me not achieving anything .... but, but in that respect, too, .... its sort of a period of rest too, I don't know.*
>
> (This is the acute illness that you're talking about?)
>
> *Yeah, oh, and a few, .... because I was in hospital the second time for six months, so um. .... I don't think I was acute the*

> *whole time I was out there, but maybe for three months or something. But its just being totally incapacitated, you know, like sort of being off the face of the earth, out in the black hole of Calcutta, in (hospital) not achieving anything, losing contact with people and .... with experiences that you probably would've been through. Although my doctor says that I've actually learnt quite a lot, and its helped me in a big way, being schizophrenic. ..//...because he sees me as quite immature and ..//.. with a lot of insecurities and things, and that actually the schizophrenia has given me, or has been a big help to that. So, not that he knew me before I was schizophrenic.*
>
> (Liz 3, p. 22)

To be totally incapacitated, immobilised, a dead person, is to be completely overwhelmed. What could be more overwhelming than a living death? Yet out of this experience involving the loss and regaining of self, came growth and change; it was literally, a life-changing experience.

Nick's answer to the question "What is it like to live with schizophrenia?" encompasses his life as a whole and powerfully presages the argument to be developed in this thesis.

> *Oh I'd say it's .... I'd say it's pretty hard, eh, because .... I don't know. .... not everybody's made perfect in this world, you know, and not everybody's the same you know, and I'd say that, you know, I'd say it's pretty hard living with schizophrenia because you're afraid that, you know, .... other people might think that you're a bit loopy or something, you know, eh? And I'd say that .... I don't know .... I'd say it's best just to do things that you believe in you know, and um .... and just ignore what other people say, you know, and just .... if they try to give you a hard time or something like that you know, I just say .... it's best to live your own life and don't let other people judge you if it's right or wrong, you know, because it's what you want to do, you know, so .... I'd say it's best just to do things for yourself, you know, and just carry on what you're doing. .... I don't know .... something like that.*
>
> (Nick 4, p. 10)

Not everyone is the same; this is the way Nick is. While he recognises he is not perfect he has no choice; he is in-the-world in this way. Being-in-the-world means Being-with-others, a situation Nick finds difficult at times because of the way others treat him, he feels about them, and the advice and judgements which may be given to or about him. In this difficult situation Nick finds it best just to be himself, to do what he believes to be right. Being-with-others is the subject of the next chapter, Chapter Five, while the concerns of participants and the choices they make in the conduct of their lives are discussed in Chapters Six and Seven.

## REVIEW AND SUMMARY

The discussion in this chapter has focused on the way in which people who suffer from schizophrenia experience their own Being-in-the-world. For the participants, to have a schizophrenic illness means to have lived through at least one period of acute illness, to have come to terms, in some way, with a diagnosis, and to take medication on a continuing basis. Although schizophrenia is commonly understood to be a mental illness, it affects those who suffer from it in every dimension of their lives. This chapter has elaborated on the bodily, mental and emotional effects of the illness, and its subsequent treatment, on the participants' sense of self. While each of the participants goes on with his or her life as citizen, worker, parent and so on, the constellation of roles depending on how their lives are constructed, they must do so against a backdrop of specific difficulties.

Each of the participants has found him or herself **thrown** into the world in a particular way. Each "exists as an entity which has to be as it is and can be" (Heidegger, 1927/1962, p. 321). Coming to terms with the realisation that one is unwell and reconceptualising one's Being-in-the-world in this light means **in-corporating** - taking into one's-self - an image of one's-self as Being-in-the-world in a new way. The distressing experiences of acute illness are followed by a profound and disturbing realisation that nothing will ever be quite the same again. Participants had to cope not only with an altered sense of bodily dwelling in the world, a state which included difficulties in propelling the body into the world, but they also found themselves occupied with thoughts to an extent which sometimes interfered with everyday activities. In order to function effectively in the world they accepted and continued to take medication which itself had unpleasant and hindering effects on their Being.

In addition to this, several participants were faced with questions about the nature of existence which for most of us belong to the philosophical realm, but which for these participants stemmed directly from their experiences of Being-in-the-world. Such questions centred on the nature of the connection between mind and body, on the meaning of one's life if thoughts and beliefs can be changed through taking medication. At times several of the participants had been brought face to face with the question of what it means **to be**, and had been brought there by virtue of the way in which they had been **thrown** into existence.

Being-in-the-world also has other dimensions. To be-in-the-world means to be-with-others. Others form a substantial part of the world into which we are thrown; we interact with others on a daily basis, but we are also part of a social and cultural ethos which has developed over time. Finding themselves in the world in the way outlined in this chapter, the participants had to engage in activities in which others were involved, and to live in the world alongside others. The meaning of Being-with-others for the study participants is the subject of discussion in the next chapter.

# CHAPTER FIVE

# BEING-WITH-OTHERS

## Introduction

In the previous chapter discussion focused on the ways in which the study participants found themselves in the world. To be in the world at all means encountering others. Being-in-the-world is a Being-with (Heidegger 1927/1962). This chapter deals with the ways in which the study participants found themselves alongside others, both in a personal sense and as part of the wider society. Meeting with others is an essential and integral part of Being and of world (Steiner, 1978). This meeting, or being alongside, others is so intimately tied to worldly existence, to Being, that it is something we often forget to take into account in the conduct of our everyday lives. It is the others amongst whom we live who are the arbiters of social norms and mores, who determine in general how "one" behaves, the way in which things are done. On a more personal level, it is amongst the others in the world that we find our family and our work mates, encounter support or rejection, and chose our friends. "The world of Dasein is a *with-world*. Being-in is *Being-with* Others. Their Being-in-themselves within-the-world is *Dasein-with*." (Heidegger 1927/1962, p. 155).

Heidegger's philosophical writings apply to human existence in general. In this chapter the particular experience of the study participants is presented. By virtue of their illness the participants found themselves in a difficult situation in the world. Historical and cultural understandings of mental illness in general coloured the reactions which others had toward each of the participants. In addition, they needed to sustain relationships with health professionals over a lengthy period of time. The illness itself impacted on interpersonal relationships for some of the participants. The notion of **thrownness**, introduced in Chapter One and revisited in Chapter Four is again relevant here. "The world into which our *Dasein* is thrown and on which it enters has others in it. The 'world's worldhood' is such that the existence of others is absolutely essential to its facticity, to its being-there at all" (Steiner, 1978, p. 88).

The world into which the study participants found themselves thrown is one where the cultural legacy of prejudice and stigma were apparent in some way to each of them. It is perhaps relevant to reiterate here that the participants identified themselves as of Pakeha New Zealand heritage, or of British or European descent. While one participant did have some Maori ancestry, she identified as Pakeha. Thus the dominant cultural views in New Zealand at the time of the study are ones which, although in some dimensions uncomfortable to the participants, were not seen as belonging to a cultural group other than their own. The implications for research into the experience of schizophrenic illness amongst indigenous Maori or other cultural groups in this country and their implications for nursing practice will be touched on in Chapter Nine.

As has been discussed in Chapter Four, the study participants each live with their own history. The facts of having been unwell, being diagnosed as suffering from a schizophrenic illness, and continuing to take medication, are part of their lives. As will be shown, for some participants encounters with others during their illness and treatment have been, and continue to be, a significant part of their experience.

The individuality of the participants was particularly apparent in their discussions of their Being-with-others in the world. Being-with-others is always a reciprocal state. Not only did the participants experience the effect of others in their world, they also form part of the world of others. Each had his or her own network of relationships, as parent, partner, worker, friend, flatmate and so on, as well as being one of the anonymous "they" amongst whom, as humans, we all find ourselves. Each participant also found his or her own way to accommodate to the demands of others in the world.

The themes under which the data are presented in this chapter are: **living with the prejudice of others; Being fearful of others; feeling uncomfortable in the company of others, staying engaged with others in the world, depending on others for help, finding others who understand** and **Being one's-self in the world.**

## Living With The Prejudice of Others

Each of the participants in this study made reference in some way to the social climate in which they found themselves, and the manner in which people with mental illness are perceived by society. Since the participants themselves are members of this society, some of the discussion related to people with mental illness in general, and was not necessarily related to their own particular situation. Stigma and prejudice were acknowledged as a part of life for *anyone* with a history of psychiatric illness. Some of the difficulty experienced by the participants was thus seen not to be aimed at them personally, but to have stemmed from their inclusion in a group, as *one who has a mental illness*. There were instances, however, where the injustice of this situation - of suffering from the prejudice reserved for a particular group - was taken and felt personally. The injustice of being judged or pre-judged without an individual hearing is clearly expressed by Jack:

> *There's a Dutch professor of psychiatry came out to New Zealand about .... I read this in black and white you know, it's not verbatim* [sic]. *I read in a publication about six or seven years ago and* [he] *said New Zealand hasn't left the starting blocks in mental health; a Dutch professor. And there was a professor Saltz or some name like that, in America,* [Szasz] *a rebel of the medical profession, he talked about the sheer horror of psychiatric oppression. I've gone out to the mailbox to get mail and two young kids, boys, have been walking down the street, .... you can't blame the children, they don't know anything about the world, but their parents have been talking, and they took off flat stick down the road "Look out, the madman's coming." See that's not helpful. It's ignorance, I know that. Well it doesn't do me any good 'cos I've never been in trouble with the law see, I've never broken the law. Well, ah .... even John K.* [an acquaintance who headed a psychiatric survivors' group] *says ..//.. they're having trouble getting a new headquarters. ..//..and they're having trouble getting a new headquarters because people have been objecting. There's no disgrace in any disability of any kind, the disgrace is in what's done about it. And you could talk for hours about that side of things.* (Jack 1, p. 6)

Jack's concern with the law was repeated during several of his conversations with me. In the quote above he emphasises that he has never broken the law. In the following passage he points out that he is vulnerable to the law even when he has not broken it.

> *When you've got a broken arm you're .... That's the point I was trying to raise with you. If you've got a broken arm, no problem. Well apart from the broken arm. But if you've got schizophrenia well you're broken up here (taps his head) but you have the social ..//.. disability too, because a lot of people don't want to know you. If you're .... mental health* [sic] *they don't want to know you, and then of course the law is a little bit .... it's some resemblance to the Dark Ages, isn't it? I mean they persecute you because you have one particular kind of disability. Schizophrenia, or manic depressive or whatever. They do penalise you for it.*
>
> (The law does too, you reckon?)
>
> *Yeah it does. The law does, yes.*
>
> (In what ways, Jack?)
>
> *Well the police can walk into this house and say, put me in jail and take me ..//.. before two doctors and put me in a mental hospital if they are so minded. If they're of the same opinion. That is the law. Not because I've got a broken arm or because I've been down and got a pound of sausages, because I've got nerve trouble. ..//.. I've been persecuted because I have a different kind of ability* [sic] *to what some people have got.*
>
> (Jack 2, p. 1)

Although Jack's concern with establishing that he has never broken the law is an idiosyncratic one, other participants were concerned that there is a perception of people who have had a mental illness as being violent. Simon, Liz and Michael all laid a large part of the blame for this perception at the feet of the media. During the period in which data were collected for the study media publicity regarding psychiatric patients was high. Comments made by Michael and Simon illustrate their concern about the content of statements in the press:

> *When you read about schizophrenia in the newspapers now there's always something negative attached to it, well nine times out of ten anyway, and .... ah .... this is how people form the impressions in their mind that schizophrenia means something bad and wrong and ..//.. things like that.*
>
> (Michael 3, p. 13)

> *The newspapers ..//..* [names two recent pieces] *seem to be reinforcing the idea that all psychiatric patients or expatients are capable of unpredictable violence. This is factually incorrect and has done a great deal of damage and is setting things back many years. ..//.. It's factually incorrect and I am thinking of taking something to the press council to see what they would do with it. And psychiatric patients are being made a scapegoat. Society is rightly concerned about all the violence in society but they focus on psychiatric patients because they are not going to answer back, they are totally vulnerable and therefore it's a scapegoat.*
>
> (Simon 2, p. 1)

That the perception of the mentally ill as dangerous or in need of separation from society is one we have inherited from our historical past is pointed to in Jack's reference, above, to the Dark Ages. Similar fears are reflected in Judith's expression of relief at finding that she was not to be taken away from her family, an outcome she had been frightened of when she first became ill.

> *Like years ago, people would just lock you away. And they wouldn't care. But now, now I couldn't believe that I could take my medication and not get put away. I was really afraid of that. I couldn't have handled that, being away from David and Rosie* [her husband and daughter], *we're quite close.*
>
> (Judith 2, pp. 6-7)

Nick has a general summation of the way he believes people see those with schizophrenia. While he does not explicitly relate the prejudice he infers to his own case, he does divorce himself from the view that he believes the public has:

> *Oh I think that they think that they're all nutty and they should be locked up, you know, like at (hospital) probably you know, and people think that oh they're just losers and all that you know, and they're no good and all that. But it's not true, eh, you know? People with psychiatric problems have feelings too, you know, they live every day, you know, and I think people are just a little bit .... they just maybe like to give them a hard time or something, you know, eh, or they can't do anything or all that, you know eh? I think that people with mental problems have feelings too, you know, eh, and um .... they like to be .... do well in life you know, eh?*
>
> (Nick 4, p. 9)

In this extract Nick uses the word "they" to refer to people with schizophrenia and to the public at large. The public "they" to whom Nick refers may be equated with Heidegger's *das Man*, translated as *one*, *anyone* or *the they*. "They" are the others who make up the anonymous public understanding, who set the standards for the way one behaves, speaks and conducts oneself (Frede, 1993). As will be shown in the discussion at the conclusion of this chapter, and again in Chapter Seven, the participants in this study found themselves in an unusual situation with regard to *the they*, a situation which has ramifications in terms of the authenticity of their lives, and which results from the extremely difficult experiences which constitute their Being-in-the-world.

The stigma and prejudice which colours the general public's understanding of schizophrenia had specific effects on the everyday lives of the participants in this study. Several people spoke of the difficulties in finding suitable housing which is common to people with psychiatric illness. Others have had to face the question of "coming out," a term I have borrowed from the gay movement, at work or among friends. As large psychiatric hospitals are closed and more people with psychiatric illness are seen in the wider community it seems likely that stigma based on ill-informed notions of what mental illness means will begin to fade. Similarly, and here the parallel with the gay movement is strong, the more people who admit to mental illness, the more visible and thus unremarkable the condition will eventually become. While several participants recognised that there were reasons to be open about their illness as a way of increasing the visibility of mental illness and thus, eventually, of reducing stigma, the urge for self preservation is strong and participants voiced their concerns and reservations over telling people of their health problems.

> *Stigma is a big thing. I'm very careful about who I let know. In fact when I meet a person I associate with them for a few months before I more or less let them know that I've got it. In fact some people I don't let know at all because I know what their reaction will be. Due to lack of .... ignorance, ah ignorance really. It's sort of that situation. We were walking back from the park the other day with the dog and there is a school teacher down the road here and he said to me, I says "Gidday how are you?" and he says "OK" he says, "but I don't like this schizophrenic weather." He doesn't know I've got schizophrenia but I feel like saying to him "Look do you know the real meaning of the word schizophrenia?" He's supposed to be educated you know, and that's the sort of thing you have to put up with. In other words he was relating to the weather as being in two minds and having a split personality sort of situation.*
>
> (Michael 2, pp. 1-2)

Michael's reaction to what he takes to be an offensive and uneducated use of language is similar to that of many groups in recent times. In the same way that feminists or the physically disabled have challenged society over the power of language, Michael's sensitivities are alerted regarding the misuse of language which is potentially stereotyping, stigmatising and ill-informed. Simon is also circumspect over who he tells about his illness. He found it useful to tell the whole truth to his employer in order that support might be there if needed:

> *I don't think I've ever told deliberate lies about this, though there may have been times when I sort of skate around the truth, and more to respect other people's sensibilities than my own. Ah .... It's a difficult one. It was pretty risky because, there was one time when I had an interview for a ..//.. job and they asked me what sort of illness it was I had that I mentioned*

> *in my CV so I said it was a schizophrenic illness and I think one person thought I should have got the job perhaps. ..//.. But there's a pragmatic reason for telling, that in reality you're going to get rejected a lot of times in the jobs market, because of discrimination and prejudice and so on. But when you find someone who doesn't do that, it will be someone who will look after you well as an employee. So I mean that's not a general recommendation for anyone who's in the situation but is one argument for telling, for telling the truth.*
>
> (Simon 1, p. 5)

On the other hand, Simon also believes that personal relationships are not possible on a basis other than a truthful one.

> *In my case no-one can really get to know me until they have taken this on board. ..//.. It is very close to who I am. I had a very weak personal identity until I started to come to terms with this. The illness was breaking up my identity, and a lot of my identity now is having come to terms with this, beaten it.*
>
> (Simon 2, p. 5)

Although he does not always tell people of his illness if he feels the need to protect their feelings, Simon clearly finds it more comfortable when he can be honest about it. He implies that having schizophrenia is part of who he is as a person and that to hide that would be to present only part of himself to others and to the world. He also feels the need to behave with the same integrity as a public and a private person.

Chris is acutely aware of the ambiguous situations in which he finds himself; as person and as schizophrenia sufferer. While he believes people treat others as they find them on an individual basis, he has also come across some unexpected and unfavourable reactions from others when he has spoken up about his illness.

> *People treat you as you are. The ordinary people treat you as you project yourself. And they might have .... they might say things about the mentally ill, but when they're confronted with a mentally ill person they don't act on their prejudices they act on*

> *.... on their social skills. OK but when I'm looking for a flat or something, and last year I was in a mental hospital, and I say .... women especially I say, you know, they say "Oh what were you doing last year?" and I say "I was on an invalid's benefit" or I say I'm on an invalid's benefit now," and they say "Oh yeah, what's wrong with you?" and I say "I'm a schizophrenic" and they just freak out.* (Laughs). *Most people just freak out. And I can't understand it because OK I was unwell, let's say I was unwell, but I always liked people who had been in mental hospitals, I admired them and so .... so .... and I'd been brought up in the same system as everyone else and I'd worked very well within that system and I'd come out admiring the mentally ill but most people come out fearful of them it seems.*
>
> (Chris 2, pp. 23-24)

Adrian was the one study participant least accepting of his diagnosis. He spoke little of feeling prejudice from others, yet did admit that he believed that if he had schizophrenia it would colour the impression his employer had of him. The admission that this was a possible outcome suggests that Adrian has, in fact, taken on the attitudes of *the they*, understanding that he might be subject to prejudicial treatment if he were ill.

> *As I say I don't think it was schizophrenia as such, I'm not an out-and-out schizophrenic, I've just got some of the symptoms that are compatible with the disease that's all. And it hasn't affected my work history so far, as I say. Because I hadn't declared it to the employers. ..//.. If I was an out-and-out schizophrenic I think it would affect my work history.*
>
> (Adrian 2, p. 4)

Each of us holds particular attitudes toward the others around us. Against the backdrop of others in the world in a general, anonymous sense, we must maintain specific relationships with particular people. In some important respects past experiences of illness and treatment had coloured the ways in which participants in this study related to others. Some participants felt fearful of others, some found most social situations difficult, and most in some way or other relived past hurts related to others in-the-world.

## Being Fearful of Others

As was emphasised in Chapter Four, the experiences participants had undergone as a result of acute illness related to the whole of their Being. During acute periods of illness several participants had suffered from extreme difficulties in their Being-with-others-in-the-world. While some of these experiences might be categorised by clinicians as delusional, they were an integral part of the experience of the people concerned, and were neither felt nor interpreted as anything other than real. Nick had had to leave an overseas trip and a blossoming romance because he was threatened by a man he did not know and whose actions he did not fully understand. He continues to find people unpredictable and frequently quite threatening, and related several anecdotes regarding the way he had been shouted at in the street, or how people he did not know had made obscene and frightening gestures toward him, for reasons he did not understand. He has had to alter several of his everyday activities such as his usual cycling route to avoid some of these people. Whatever judgement might be made by others regarding the reality of each of these events, they are real experiences for Nick.

After treatment during an acute episode of illness Judith found she was often unwilling to talk to others. As she explains, she feels different now, but remembers that at the time she was unwell even shopping became an alarming experience for her.

> *My mood's changed. Sometimes I can't be bothered talking to anybody. But I know that that's a cop-out, for me. I'm a lot happier than what I was in myself. I've always been happy with Rosie and David and my homelife. But it's just getting to know myself again I guess. Because I can remember that we used to walk down to the supermarket and get our groceries and this was when I was into the zodiac, I was into spiritual stuff, and I still believe in it, I still believe that there is something there. But I remember I used to walk around, and I'd know that these people were looking at me. I used to get really paranoid, and they were all dressed in black, and I thought, that's why I used to freak out so much, because I used to think someone was after me, and I that's what it was like in (town), everybody was dressed in black. I thought that there was somebody after me, I*

> *really, .... and I said to David, "Why do they keep staring at me?" and he said, "Why, what's going on?" And I said "I feel as if there's a hit after me." That's what it was like. The voices were like that. "We're going to get you."*
>
> (Judith 3, pp. 7-8)

As Judith indicates here, her experiences of being afraid had ramifications for her relationship with her partner, from whom she could not hide her fears. His supportiveness was something she acknowledged frequently in talking to me. Judith also mentions voices here. Voices are **of others**. Whenever any of the participants heard voices in the acute stage of their illness they were related to other people. It was not until recovery had begun that voices were recognised as generated by their own thoughts. Thus, if the message given by the voices was a frightening one, other people were interpreted as intent on doing some harm. Participants had reason to fear other people in this circumstance.

Jack has never heard voices but he, too, expresses a fear of people. In fact this is what his illness is about as he sees it: he is vulnerable to people.

> *Yeah I've been diagnosed as that's what's wrong with me. By one psychiatrist. Fear of human beings. You know how you have fear of heights and fear of open spaces and .... I have fear of people. I hardly ever mix. Well I do mix if I think a person's Christian and all love it doesn't worry me too much. But if I .... like for instance I don't like going down the supermarket. I hate it. Just hate it. I'm all right at the beach with a special cobber, all day, I don't .... I don't mind it. But I don't even like walking .... I'm walking up the street I'd cross over the .... there's people coming, quite often I cross over to the other side. That's what I mean. I've always been like that, even at school, school dances and all that, ..//.. I was in me* [sic] *element deer stalking way up in the bush, you know, and ah .... inhabited areas are not my cup of tea.*
>
> (Jack 2, p. 5)

Not all the participants in the study were as self-aware or as fluent as Jack but several described their difficulties in Being-with-others on a personal level. Being met with kindness makes a huge difference to how easy it is for Roger to socialise. As he explained, he wants to meet people yet is hampered in achieving his goals because of his fear of others and his own lack of confidence.

Here Roger detailed what he does in a usual week. He went to a video group at church on Friday and a games evening there on Saturday:

> *But I don't do very much myself, actually. I get my groceries and try to get in with the church, try to get in with the community a little bit actually, I don't really force myself, but since I've been with the Methodists I've been doing lots of, I've got quite a lot more confidence in myself, and I'm not as scared to meet people as much as I used to be, which is a good thing. And I want to meet people, I want to help somebody, through the church somehow.*
>
> (Roger 2, p. 4)
>
> (Lets go back a bit. You said that you've got more confidence since you've been in the church. Is that because the people are nice to you?)
>
> *They're kind. They're kind, the people are kind. They don't look at you like you're a dog because you're mentally ill. What's been or gone or what's going to happen, they're interested in what's happening now. That's right.*
>
> (Roger 2, p. 5)
>
> *I checked up in the diary the other day and it said that .... I've only been with the church two months, and I've .... come from the back row of the church right to the front, sitting at the front of the church .... and listening right through the whole session, instead of running out, I mean that's how I was when I first started.*
>
> (You couldn't manage to sit down when you first went?)
>
> *I couldn't sit down at the start there, frightened of the people, that's what I was, you know.*
>
> (Roger 3, pp. 2-3)

Roger's fear of others and the success of his own efforts in dealing with his fear has some important implications for nursing. The discussion in Chapter Eight recognises the need for nurses to acknowledge the fear of others experienced by those with schizophrenia and to help people like Roger to deal gradually with such fear and discomfort.

## Feeling Uncomfortable in the Company of Others

Less intense than fear of others, yet more common among the participants, was an expressed feeling of being uncomfortable in the company of others. This feeling took a variety of forms. Some participants found it difficult to meet new people, some to establish relationships with the opposite sex, some to sustain friendships, to set limits within them or to be physically in the company of others in any but a casual way such as that which occurs when shopping or drinking at the pub.

Lucy is a sociable young woman who usually enjoys the company of friends and family. As she recounts, however, feelings of paranoia have lasted past her acute illness and impact intensely on her feelings of security and self confidence. Lucy uses her sister to check out her feelings about other people, as did Judith with her partner.

> *And it's still terrible when you hear people laugh when you walk past. You think shit, they're doing it to me. That happened all the time. And I don't think it's being paranoid. I really really don't.*
>
> (You don't? It's really real?)
>
> *Yeah. If somebody laughs when you walk past they're not laughing 'cos they're telling a joke, they're laughing 'cos they're laughing at you. And like yesterday with my sister. I said "Amy have I got my fly down?" I said "Why do these people keep gazing into my eyes?" It's not because they're in love with me. They don't know me. You know? ..//.. And it seemed so obvious. And people assume you're being paranoid. But they don't know what paranoid is. They really don't.* (Lucy 1, p. 28)

The study participants did not all have difficulties with others based on continuing paranoid feelings or lack of confidence. Because of their individual personalities and the variety of symptoms associated with their illness each participant described a unique constellation of experiences. Nevertheless, all the participants found some difficulty in relating to others on an individual basis, in the same way that all were aware of the prejudice which is attached to mental illness in this society.

As Simon described in the previous chapter, the very fact of having experienced an acute schizophrenic illness changed his view of the world and his outlook on life. This in turn has had an effect on his relationships with others. On a more pragmatic, but no less important level, Simon has an ongoing sensitivity to noise. He described how this interferes with everyday life with others.

> *I think there has been an enormous cost in terms of personal relationships .... which I don't know if I will ever resolve .... it's partly because an experience like that* [acute illness] *puts you on a level of seriousness that frightens most people I think. And partly it is on-going problems of extreme sensitivity to noise, and too much talking and so on. Most of the circumstances in which you meet people shut me out. ..//..*
> *So it's a bit of a dilemma about how to get social fulfilment without getting overwhelmed by too many noises and impressions and so on.*
>
> (Simon 1, pp 3-4, 9)

Simon postulated a further reason why he and others with a schizophrenic illness might feel uncomfortable in interacting with people. He relates the time at which illness often first occurs to a critical time of learning to conduct social relationships. While no other participant voiced this relationship quite so clearly, several did suggest that they had "lost" periods of their teenage years or early twenties. Simon suggests that prejudice and hostility are not simply the cause of poor relationships, but that they have damaging effects on those who are subject to them:

> *Because there is a critical time at the end of one's teens and into one's twenties when important things are happening about learning about how to make relationships, learning about higher education, getting one's first work experience. If one becomes so seriously ill in this sort of way, even if only for a month or two it may set you back in a way that you never recover from, especially if you have overt stigma and prejudice and hostility as well.*
>
> (Simon 2, p. 5)

Because schizophrenia so often begins during the teens or twenties, Simon's caution that there is a danger of long term social damage is particularly important. The nursing implications of Simon's observation will be addressed in Chapter Eight.

### Staying Engaged With Others in The World

Whatever difficulties they met in living with others in the world, all the participants made an effort, according to their own personalities and preferences, to stay engaged with others on a personal level. Each had a circle of friends, family or acquaintances with whom they made regular contact of some kind. Staying engaged with others meant making contact with others, sustaining the relationships they found rewarding and taking a stand on matters of debate when the outcome mattered to them.

The wide range of talents, living circumstances and ages of the participants in the study meant that there was a correspondingly wide range of personal social circumstances amongst the participants. Those participants who worked in paid or voluntary capacities talked of sustaining relationships related to this aspect of their lives. Adrian had deliberately chosen work which he could conduct from home in his own time, thus avoiding some of the pressures he had previously felt from co-workers and bosses. Several of the participants who were not employed spoke of pressure from others as being one of the factors they could not handle and identified such pressure as a reason for their not working at present.

Family was an important source of social contact for each of the participants. It was from family members that the participants received much of their support and to them that they turned for feelings of usefulness. Michael, Simon and Judith were all parents and spoke warmly of their children and the pleasure they brought to them, as well as the responsibilities this entailed. Lucy lived at home with her parents during the period of data collection. Her relationship with her parents was similar to that of many young people her age; both stormy and warm. Two of Lucy's sisters in particular were also important members of her social circle. As has been mentioned, Judith found the support of her partner invaluable in coming to terms with her illness in all its aspects.

> *You know, he puts up with a lot from me with my moods. You know, if I'm, like if I have an attack it could last from anything for three hours, four hours. And I'm sitting there and my face is looking like thunder. I'm not saying anything, I'm angry at myself, I'm blaming myself. But once it's gone .... he knows. He does know now when these things do come. And he said "All I can do is give you my support. That's all I can do. And I can be there with you." But he said he doesn't understand it.*
>
> (Judith 4, p. 27)

The reciprocal nature of relationships with others is demonstrated in this explanation of Jack's daily exchanges with his elderly aunt whom he visits frequently and of whom he is very fond.

> *Well I see my aunt every day. I ring her up every morning. I get up at half past seven - I ring her up 'cos she's eighty some .... eighty odd. And she hasn't got good .... She gets around but her health is .... you know, age. I ring her up every morning, I ring her up at least once before dinnertime and I ring her up once before nighttime, check on each other. ../.. Yeah she's my closest .... ah she's the only one of my relatives that I really want to know.*
>
> (Jack 2, p. 13)

The everyday relationships of participants with their family and friends were described in ways which were unremarkable. It seemed that, on the whole, these were relationships which just carried on as do the relationships of those who have never suffered from mental illness. As all people do, the participants treasured relationships in which they felt understood but worried about, or avoided, those where they were met with unkindness or misunderstanding. The long term nature of their illness and the need for participants to continue to take medication on an ongoing basis meant that most had fairly frequent contact with health professionals or lay health workers. In addition, all but one of the participants had maintained some relationships with other people who suffered from schizophrenia or another mental illness. Both types of relationship were particularly important for most of the participants.

## Depending on Others for Help

Relationships with health professionals and lay workers from areas related to health and housing were addressed with ambivalence by most participants. The nature of the illness which had necessitated ongoing relationships with these people is an important factor in this regard. Each of us carries our past with us into the present and the future. In projecting ourselves toward the future we understand ourselves and the world from out of the experiences we have already had.

> According to Heidegger, we cannot make any such projections without an existing understanding of the world and ourselves in it, an understanding determined by the past we have been and still are. Therefore, not only do we carry our past with us, as one carries weighty memories, but we always already understand ourselves and our projects in terms of the past and out of the past.
>
> (Frede, 1993, p. 64)

Each participant in this study had been deeply affected by the experiences which constituted their acute illness. The effect on their Being-in-the-world and their sense of self was addressed in the previous chapter. But there is another dimension to this kind of illness. Each of the participants had spent time with health professionals when their diagnosis was made and prior to it, and has maintained contact with people in the health service ever since. What kind of experiences these contacts have turned out to be is dependent to some extent on the age of the participants and the severity of their initial illness. Several of the participants have had the experience of involuntary hospitalisation, and some have since found a home in supervised accommodation in the community. As the oldest of the participants, Jack has some of the most disturbing stories of hospital life; he was hospitalised in the era of large hospitals and unmodified ECT. That Jack remains fearful of health professionals until they prove their trustworthiness, and that he is acutely aware of their potential power over him is not surprising, given the past with which he lives. When ill he had also been frightened of other patients such as the homosexuals and murderers to whom he refers in the following passage:

> *Yeah, well I've met some very fine Christian people you wouldn't mind you wouldn't mind .... meet finer, but I've met some terrible people. Murderers, and .... in mental hospitals I've met them. That's a thing you asked me once about what did I mean when the administration is so poor and if you go into a mental hospital there's all walks of life, there's doctors there, there's ministers of religion, I saw them at (hospital) all bitter against the world, ah .... there's murderers, there's homosexuals, there's religious mania cases, there's 1400 patients at (hospital) when I was there. ..//.. When I left to come out, to come home, when my people came and got me I had to sign meself* [sic] *out and this doctor sat in the Villa down there and I signed a paper and do you know the last thing he said to me? And he didn't say it, he barked at me like Gestapo interrogation: "Do you hear voices?" Well of course I heard voices, I heard his voice asking me if I heard voices. But he was .... I mean they go nutty these doctors, they're actually nuttier than the patients. And yet they have the power to hold you there indefinitely.*
>
> (Jack 2, p. 5)

Jack believes that at the time he was hospitalised some patients were left to die in appalling conditions, the staff unconcerned and uncaring about their plight.

> *I've seen the linen, the ah .... the sheets from some of the wards. The blood and manure, they* [patients] *are just vegetables, you touch them and they die like it. It's a total break down. But they* [nurses] *don't appear to bother with it. As far as I'm .... I'm not sure on this point, but I don't think they make any effort to do anything.*
>
> (Themselves?)
>
> *The staff. ..//.. I can't .... I can't say that publicly for certain, but I understand there's something like that happens. They just don't bother with it. Not that they really bother with anybody.*
>
> (Jack 3, p. 6)

In spite of such distressing experiences in the hospital in his youth, and the fact that he recalls these experiences frequently, Jack talks fondly of the community nurse whom he sees at present and is able to turn away those with whom he feels things will not go well. He joked with me about the fact that nurses he knows locally are "nurses," this, as he explained, was a compliment; the nurses at the hospital spoken of above were "guards" in his eyes.

> *Oh I get on with Robert* [community nurse]. *Yeah there's a .... the community team ..//.. are a totally different kettle of fish. There's only one of the ..//.. team that I've had any difficulty with and that was a social worker, I forget her name, she came here one day and she .... "Oh the table's got to be cleaned, your .... your shirt's not right," you see, "it's not clean" you know. I .... I don't have her now, I got rid of her. I was polite about it, tactful, very tactful, yeah I .... I got out of it. .... She was a nice girl and she meant well, she was a social worker, her was way was to turn me out for a State Luncheon I suppose, sort of caper, being a woman you see, but I'm a bachelor so I didn't appreciate it, being pushed around in a mild sort of a way.*
>
> (Jack 3, p. 7)

Because of the differences between study participants' histories and personalities, and because of their individual experiences of interactions with health professionals, each participant reported different views of the help they had met with in the health care system. Several participants had found health professionals generally helpful and kind. In the following interview excerpts Chris expresses his appreciation of both psychiatrists and nurses:

> *Well they* [psychiatrists] *do have a lot of power but they are probably the most unassuming and rational purveyors of power that I've come across, you know. Um .... they'll let you off* [do not insist on hospital treatment], *if you can communicate with them at any level they'll let you off completely, they won't put you in hospital or anything. It's only when you are a total wreck that they'll put you in hospital.*
>
> (Chris 2, p. 4)

> *Nurses were really keen, maybe not to reveal themselves but to find out about me, they were willing to listen to anything about me. And um now that I look back at it I think .... I feel now I was in a really secure environment. It was a horrible environment ..//.. but it was also .... they were doing their best for me and they were going out of their way to find out who I was, what I was so that they could get me back to being that.*
>
> (Chris 3, p. 13)

In general, participants appreciated health professionals who were honest, friendly, kind and helpful, especially when the help was of a practical, problem-solving nature. Actions which were perceived as controlling were not appreciated. Here Liz describes the way she and her boyfriend began to dislike being told what to do, or having to ask permission to go out, during their time in a supervised hostel:

> *We sort of started to pull away from the situation where we were told what to do every day and could we go out to the dairy* [corner shop] *and get ourselves a packet of cigarettes, you know. And um .... you know what .... generally what time we went to bed and you know, what we did and where we went and who we were seen with .... ..//.. She* [nurse] *never really lets go,*

> *you know, she sort of always treats you like a patient or something like that and you just .... you just want to rebel, or that's how I felt. Sort of .... nurses .... nurses are sort of special type of people, I think it's just the way they are, you know, look after people, care .... be caring and you don't always want that round all the time. And .... that's sort of a professional relationship, you know, you sort of get sick of those, sort of want something more personal. Someone that you can really .... get a real opinion from, you know, not that you can't from professional people but .... it's not so sort of clinical or .... you know.*
>
> (Liz 2, p. 8)

Liz's references to the nature of care and caring demonstrated by nurses and her distinction between professional, "clinical" relationships and personal ones is important and will be discussed in Chapter Eight in light of the implications of the study for nursing.

Examples of welcome practical help offered to participants included a nurse's advice about sleeping habits, a lay health worker's help with gardening, and suggestions about diverting thinking patterns away from frightening thoughts which a visiting church member provided for one of the participants. One of the important areas where health professionals were seen to be helpful was in encouraging participants to socialise with others. Simon suggested that he would have liked his doctor to have modelled friendship for him; to have helped him learn what constituted a successful friendship. Liz acknowledged the help that nurses had provided in teaching her to get on with others while she was in hospital:

> *We are sort of taught ..//.. that socialising is very important, so you know .... I mean you can just sit there and say nothing and just smoke and drink coffee and just sit in the corner or something, but .... once you start asking questions about yourself you start asking questions about other people as well, so .... you start to take in what's happening around you rather than what's happening in your head all the time. ..//.. Because it's the easiest thing in the world to go and lie on your bed and just sort of do nothing.* (Liz 1, p.12-13)

Health professionals in some ways, then, not only formed part of the participants' social world, they also encouraged participants to stay engaged in the world in a wider sense.

## Finding Others Who Understand

Although relationships with health professionals were seen as positive on the whole, the majority of the participants had another, perhaps more important, source of comfort and support. It was with others who had undergone similar experiences that they felt most at ease. Those participants who had built up a network of others with similar experiences suggested a number of reasons why this was so and reported that their network of friends provided a number of benefits. One or two participants, however, were anxious to extend their social contacts to the "normal" world and two participants did not socialise at all with others with a history of mental illness.

That people who have undergone the traumatic experiences which are part of serious mental illness and treatment should get to know each other and make friends is really not at all surprising. Not only do they share some kind of common history, but they have often been thrown together in hospital or community treatment or accommodation centres or have met through groups such as Psychiatric Survivors or Schizophrenia Fellowship.

Judith explained the relief she felt when she was first introduced to someone who had had similar experiences to hers. Talking to another young woman who had known similar fears made her realise she was not alone.

> *I thought well here's somebody who understands. ..//.. And you don't feel alone any more. Because there's other people around that, I guess it's because you don't hear about it. You don't hear about these things, people just don't talk about it.*
>
> (Judith 1, p. 10)

Michael suggests that people who have similar illness experiences have a common base of understanding which facilitates friendships. Michael's statement that these friendships are open and honest and do not involve secrets is echoed by Chris's comment, below:

> *I think a lot of the sufferers, especially the older ones tend to socialise more than the younger ones and they ..//.. they build up a type of a friendship amongst themselves. Because they're all in the same situation and they know what's wrong with one another and they've got no secrets to keep and all that sort of thing. So they build up a friendship ..//.. several friendships.*
>
> *Well you're suffering, you suffer the same illness and the same symptoms and you're under the same circumstances so there's nothing really to hide from one another. Not like a lot of .... well you couldn't really call them .... but acquaintances keep their secrets from one another and they don't really tell each other, you know, what's going on in life ....*
>
> (Michael 5, p. 1)

> *We've been laid bare in front of everyone. Our most secret thoughts, we've blurted them out, there's nothing secret any more. And that's another thing about being with other schizophrenics in a club or something you know we're all relaxed, we're all relaxed, there's nothing we can do that could be more embarrassing than the things we've already done.* (Laughs)
>
> (Chris 3, p. 13)

Jack is the centre of a network of people who have had psychiatric problems. He sees his friends as trusted people; they are chosen. He shares his worries with two friends in particular; these are people who share some common history and so understand each other in a way which those who do not have a similar history cannot do. Jack's description of his difficulty describing this experience emphasises the extra-ordinary nature of the experiences he and his friends share in common, from which I, as researcher, was excluded.

> *They're both psychiatric. The three of us have had shock treatment, the three of us have been in mental hospitals and oh I've known Eddie for 50 odd years, but Jake I've only known about ten or twelve. But they're of good character. ..//.. We've got things in common. We both .... the three of us know what*

> *it's like. Actually you don't know what it's like and no person that hasn't been through it .... and .... and you can't put .... describe it fully because you can't picture it. If I said "Oh I've got some white roses growing out the back" you'd know what I meant. You'd have seen them before and you look at them and they're roses. But ah .... you know, unless you've been through it you don't know what it's like. ..//.. I can't find the right words to completely give you a good idea.*
>
> (Jack 4, p.15)

Liz lives with her partner who also has a schizophrenic illness. She had found that many health professionals tried to discourage their relationship, on the basis that they each needed "normal" friends. While she agreed that it was sensible to mix with other people who were not unwell when the chances presented, her relationship with her partner was important to her and they planned to marry in the next two years or so. Liz expressed some exasperation at the way in which this relationship was frowned on by people who were in the role of helpers. She saw her relationship as comparable to any other:

> *We sort of went to half-way houses and hostels together. Because we got sent there by the hospital because we were committed* [for treatment]. *And sort of took up friendship and love and now marriage. There's lots of views though, that we shouldn't be together, that two schizophrenics shouldn't be together. That how can we possibly have a normal life at all because we're schizophrenic. And that things will be pretty hard for us to get anywhere. Seeing as we're both mentally ill. Got a problem. But we've got a pretty good life and all that. Most of the time it's good. It's like everybody really, there's always ups and downs.*
>
> (Liz 5, p. 3)

There were drawbacks to having friends who suffered from psychiatric illnesses. Several people reported having become very involved in the problems of their friends, sometimes not knowing how best to help them and several had also experienced the grief which accompanied the suicide of friends or acquaintances.

Although Simon had the opportunity to meet other people who had experienced a schizophrenic illness, as he explained, he did not see this in itself as the basis for cementing friendships. As he points out, the fact of a common illness is not the basis for any kind of relationship - each person with a schizophrenia illness is first and foremost an individual.

> *One of the reasons that I keep close to that society* [Schizophrenia Fellowship] *is that it allows me from time to time to meet people there, with psychotic illnesses. But again, the fact that they've got an illness similar to you doesn't mean that they're in any ways similar to you overall, so. ..//.. It's not really an area for finding close friends.*
>
> (Simon 1, p. 7)

As was suggested in the previous chapter, mental illness was a significant part of the life of the participants, yet each also went on about the business of living in an individual style, as citizen, friend, worker and so on. The experience of schizophrenic illness did not overtake the participants' entire lives, although it was a significant component of the whole of their Being-in-the-world.

## Being One's-Self in the World.

The challenge which the experience of mental illness laid down to the participants in this study meant that coming to terms with their Being also meant re-examining who they were in the world. Most of the time this is not a question for us unless we are befallen by a crisis or some extraordinary external event. In the ordinary, everyday activities of life our social and cultural context determines, lays out for us, how and what "one" does, and this is the pattern which we follow. Heidegger refers to this tendency for all of us to act as the others, the anonymous *they*, **falling**.

> As Heidegger sees it, our "worldly" existence as "average everydayness" is characterised by "falling," the tendency to be engrossed in day-to-day preoccupations and to drift along with the fads and trends of the crowd - the anonymous "they" or "anyone" (*das Man*). In this humdrum everydayness, life is

> levelled down to the lowest common denominator of doing what "one" does in typical, familiar circumstances.
>
> (Guignon, 1993, p. 30)

In falling we forget, at least temporarily, who we are as unique individual Dasein.

> Thrown among others, enacting and realizing our own *Dasein* as an everyday being-with-one-another (Heidegger's ponderous hyphenation images the meshed density of the facts), *we come not to be ourselves*. We come to exist not in and on our own terms, but in reference to, in respect of others.
>
> (Steiner, 1978, p. 89)

As has been indicated in the discussion so far, people with schizophrenia have experiences which most people have not, and never will. Most of us have never experienced the changed bodily dwelling in the world described by the participants, nor the disturbing realisations of the connection between mind and body, at least not in such an experiential sense as was reported, for instance, by Simon in the previous chapter (p. 127). In addition, most of us do not have to live with the stigma and prejudice which is directed, albeit sometimes subtly, at those with mental illness.

Because of the life experiences they have had the participants found themselves thrown into the world in a particular way. Several of them, having come to terms with the widest implications of their illness, their Being-in-the-world and their Being-alongside-others, have learned to depend to a large extent on themselves. They work toward Being them-selves in the world, which at times means rejecting the attitudes and prescriptions of *the they*. Roger, for instance, believes that a large part of his difficulty in the world stems from his moral stance. In his eyes he is too good and clean living: *"To get on in life you've got to be bad and tell lies, and you're suppose to sleep with about five women and give them VD"* (Roger 1, p. 4).

Simon and Chris both say that they reject some of the conventions of the day, or the pressures of those around them, preferring instead to be true to themselves. Chris's observations of the growth he has experienced as a result of living through difficulty are similar to comments made to Liz by her doctor (p. 130).

> *I don't want to be normal. I consciously reject a lot of the culture around me and feel that I would fit in better to some parts of the nineteenth century than the twentieth century. And I've travelled ..//.. and have seen bits of the nineteenth century alive and well* [overseas], *things that we have lost.*
>
> (Simon 2, p. 8)

> *I want to carry on being me and not .... like in school I constantly adapted to what other people were telling me to be but I'm an adult now and I'm going to be me. Because if I adjust myself to what other people want me to be I end up as some cretinous fool as far as I'm concerned. So I'm going to be me from now on. Well I feel that I've got an advantage over them. I feel that mental health is a leading field in social adjustment and these poor tutors and everything* [refers to training course] *they're back twenty years, they're twenty years behind me. I've been through hospital, I've been to treatment, counselling, I've done it all and I feel that I socially I'm much more in tune than they are.*
>
> (Chris 3, p. 13)

Whether or not they were consciously aware of rejecting some of the values around them, all of the participants talked of their own personal values, and their hopes and dreams for the future. Each worked actively at maintaining Self in-the-world-alongside-others. The complexity of this task will be elaborated in Chapter Seven in terms of the stand the participants are taking on their lives.

## REVIEW AND SUMMARY

Being-with-others is an integral part of Being-in-the-world. Being-in-the-world is a Being-with (Heidegger, 1927/1962). It is others in the world who provide the background of social and cultural rules by which we live, amongst others in the world that we find ourselves in our various social roles, and from others in the world that we choose our friends and those who will help and support us. We are also with others even if avoiding them. It is against the usual Being-with that one may, for instance, choose to be alone.

In this chapter discussion has concentrated on the way in which the study participants found themselves alongside-others-in-the-world. Their experiences both during past periods of acute illness and those they continue to have as a result of their condition formed part of their history and coloured the attitudes some now held of others, and the ways in which they interacted with people on a day to day basis. As the discussion has illustrated, the participants struggle with the inevitability of Being-with others who do not always understand them, their need for social contact, or their desire at times to be alone. Several participants felt fearful of others and frequently avoided them. Other participants simply felt uncomfortable in the company of others. All, however, worked at staying actively engaged with others in the world. All maintained social contact in a way which best suited their personality and their circumstances. All sought the company of others who would understand something of the experiences they had had in the world, or of the preferences they had as to how to be with others in the world.

The necessity to maintain contact with health professionals meant that all participants had some comment to make about these relationships. Since these contacts were intimately connected to the participants' experiences of illness they were also tied in to that part of the participants' histories. Changes in the treatment of psychiatric illness and the psychiatrically ill over time are to some extent reflected in the attitudes participants have toward their dealings with health professionals.

In their encounters with others participants reported instances both of being met with kindness, and of feeling they had been the subject of cruelty or misunderstanding. Most participants were aware that they had had experiences which the majority of people will never undergo. As such they belonged to a special group whose members, those who had experienced a serious psychiatric illness, were at times the most understanding of their contacts.

In a more general sense others were a source of prejudice and misunderstanding. In this regard the media were seen by most to be purveyors of misinformation and consequently to encourage fear or even hostility toward the mentally ill among the public in general. The need to live with, and endeavour to overcome, the stigma of mental illness is a reality for each of the participants on a daily basis.

In this and the previous chapter the Being-in-the-world-alongside-others of the participants has been described. In our everyday activities and in looking forward to the future each of us must deal with those things which are of concern to us. Every day we make choices about the manner in which we structure our lives and about those things which are most important to us. In the next chapter the concerns and choices of the participants will be discussed as they relate to their everyday Being-in-the-world.

# CHAPTER SIX

# BEING CAREFUL

## Introduction

In the previous two chapters discussion has concentrated on two dimensions of the experience of people living with schizophrenia; Being-in-the-world and Being-with-others. In this and the following chapter the daily actions and longer-term aspirations of the participants are presented and discussed in light of Heidegger's notion of *care*.

In Heidegger's terms, care *(Sorge)* signifies care-for, concern-for and concern-with those things or people encountered in the world (Steiner, 1978). Care is fundamental to Dasein's existence. "To be human means to be concerned about things and to be solicitous toward other people" (Zimmerman 1993, p. 247).

> It is *Sorge* that makes human existence meaningful, that makes a man's life signify. To be-in-the-world in any real, existentially possessed guise, is to care, to be *besorgt* ("careful").
>
> (Steiner, 1978, p. 98)

*Care* denotes the way that things matter, our overall involvement in the world, and the sense that we give to existence. In Heidegger's writings, care *(Sorge)* is considered in an ontological-existential manner; *care* is Dasein's Being. "Dasein's Being reveals itself as *care* " (Heidegger 1927/1962, p. 227). However, in coming to understand Dasein (in this case that of the study participants) it is necessary to understand the everyday meanings of care in action; this is where the ideas of concern *(besorgen)* and solicitude (Fürsorge) for entities and people within the world - what matters to people - are those enquired into and sought after. In his work "Being and Time" Heidegger traces the common meanings of the word *cura* back to early Roman writings, pointing out that in its early usage, *care* might be understood to signify both "anxious exertion" or "carefulness" and "devotedness." These aspects of care are among the kinds of attention which Dasein pays to the everyday world in the attitude Heidegger calls "concernful absorption" (1927/1962, p. 268).

*Care* also encompasses the way we "treat everything as a part of our project in the largest sense of the word" (Frede, 1993, p. 63). Guignon (1984, p. 331) explains that to be human "is to be 'projecting' oneself toward the realisation of one's life as a whole." As long as one is alive - while life is not yet complete - there is always something which is "not yet." Heidegger refers to this state as Dasein's "potentiality-for-Being-in-the-world." Not only do we understand ourselves in terms of what we encounter in the world, we also act in a way which enables us to fulfil this potentiality-for-Being.

> Dasein is care, for Dasein is always concerned about its being. My life .... is not something indifferent to me, something that leaves me cold, as it were; on the contrary, it is something that *matters* to me. Now my life matters to me - indeed *must* matter to me - only because I am aware that I don't have it "forever" and "once and for all;" life matters only because I am aware that it can be snatched away from me by the power of death.
>
> (Hoffman, 1993, p. 200)

In this chapter *care* is considered in relation to the participants' concern for things in their everydayness, the way in which they understand themselves and their situation and the manner in which they comport themselves toward their world. In Chapter Seven *care* is demonstrated in the participants' endeavours to live out a life which signifies something and on which they take a stand. The importance of temporality in relation to care will be shown as the discussion progresses, particularly, as was discussed in Chapter Four, in the way in which the participants' histories impact on their present and their future.

The aim of this study was to examine and describe the everyday lives of people with a schizophrenic illness. For Heidegger, it is through an examination of everyday concerns that the nature of existence, what it is to be-in-the-world, is to be understood. Indeed this is the way that people understand the world in which they live:

> Our everyday life is determined largely by our understanding of all entities in terms of our practical concerns, purposes, and designs, and this includes our dealings with other human beings and with ourselves.
>
> (Frede, 1993, p. 59)

As has been shown in the previous two chapters, the study participants hold specific concerns, related to their Being-in-the-world and Being-with-others, which may be directly attributed to their illness. The experience of schizophrenic illness itself, its treatment, and the encounters the participants have with others in the world are all of concern to them in living their lives. Being-in-the-world and Being-with-others are included as elements of *care* in Heidegger's analysis. In this chapter, some of the elements introduced in Chapters Four and Five will be revisited, but the main focus of the discussion is on the choices and possibilities of the participants as they show themselves in their everyday lives.

In telling about their lives with schizophrenia, the study participants related concerns which have been divided into four themes: **living circumspectly**, **recalling the past and letting it go**, **holding on to hopes and dreams**, and **taking a stand on life**. The first two of these themes are addressed in this chapter, while the discussion in Chapter Seven will elaborate on the themes **holding on to hopes and dreams**, and **taking a stand on life**.

## Living Circumspectly

The theme **living circumspectly** includes four sub themes: maintaining a routine and avoiding stress, taking prescribed medication and refusing street drugs, monitoring thoughts, and managing finances.

To be circumspect[1] is to look around watchfully, to be cautious, to be prudent. In order to live successfully with their illness and to prevent further acute episodes, the study participants watched themselves for signs of illness, took precautions in respect of their everyday activities and made judgements and choices about the management of their lives. In this respect in particular the individuality of the participants was clearly evident. The range of choices differed for the each of the participants depending on their circumstances, personalities and abilities. In addition, their acceptance of their diagnosis, and their understanding of their illness and its manifestations in each case were different.

---

[1] The meaning here is congruent with that referred to in the translators' note in "Being and Time" (1927/1962, p. 98). Macquarrie and Robinson comment on their translation of the word *Umsicht* from Heidegger's original work. They take Heidegger's use of the word to mean "looking around" or "looking around for something" or "looking around for a way to get something done."

### Maintaining a routine and avoiding stress

Common to all the participants was a routine of some sort in their daily lives. All spoke of the need to avoid stress as far as possible, and routine was one way of accomplishing this. However, routine is not an easy thing to describe, since it is by definition a part of ordinary, everyday existence. The specific details of everyday practices became more apparent and were described by participants in relation to events which threatened to upset their routine. Simon had recently travelled to Europe, and was planning another long trip when I spoke to him. He explained that he needed to take extra time to overcome jet lag and always planned this time into his travel arrangements. This was not simply a question of his personal comfort, but related to his need to be careful with himself in order to stay well and to function at his best.

> *Regular sleep is very important. I try to plan everything so that it goes on a regular routine. I'm not very good at doing without sleep. Air journeys and so on, which I find myself doing, when I do travel, I try to plan it so that I have plenty of time to get over the travel.*
>
> (How long would you need to recover after a long plane journey? How long is a reasonable time?)
>
> *Ten days, twelve days. It is said that you need one day for every hour of time change. I think many people can get over it much faster than that, but that's about right for me.*
>
> (Simon 1, pp. 8-9)

Chris explained that routine is a part of being well. He has learned to take things one at a time and finds that he is now able to "live up to a routine." As a result of this kind of an outlook and this way of tackling things in a step by step process, Chris now believes he would be able to work fulltime if the opportunity should arise. It is likely that the nurses and other health professionals who helped Chris learn to approach his life one step at a time actually saw the routine as a way to help him live his life, and that the routine was a means rather than an end in itself. For Chris the stepwise process of living this kind of routine has proved something to be worked at, and in itself symbolises his being well.

> *And so I came up here and I got some part time jobs and so now I feel that I could do a full time job, but you know, that's what I feel ..//.. and I've learned to do that by just living one day at a time, not worrying about the whole rest of my life, just to say OK I can do it. .... I'll wake up in the morning and worry about the job then. Or else no, I won't even do that, I'll just wake up and worry about brushing my teeth, then I'll worry about catching the bus, then I'll worry about travelling, then I'll worry about work when I get to work. OK I'll think about work, and I'll think about what I should be doing, but I won't worry about it.*
>
> (Is a routine part of that?)
>
> *Yeah. Living up to a routine is part of being well. And in the past I couldn't live up to a routine because I'd say "God I can't face getting up in the morning, tomorrow morning, I can't face it." But now I say "Well who cares about tomorrow morning, it's night now, I'll just worry about tonight." And I couldn't do a routine before because it was just too hard.*
>
> (Chris 2, p. 18)

Different things were found to be stressful by different participants, yet the management of stress, or the avoidance of situations which could be expected to be stressful, was important to all the study participants. Liz has found that she cannot work fulltime as she still suffers some residual symptoms which are exacerbated when she is under pressure and which then interfere with her functioning. She emphasised the difficulty she faces, which she generalises to anyone with schizophrenia, as being more intense than that of people without the illness.

> *I see sort of like, little blue sort of circles or sort of irregular shaped sort of blue things in the air, so they are sort of hallucinations, but I don't really think much of them, it's only when I'm really rushing around or really sort of stimulated, and see them that they're a bit of a problem, because it's a lot of things happening all at once, you know, takes me back a bit.*

> (A lot of things happening all at once, is .... stressful?)
>
> *Yes, is that a sort of definition of stress? ..//.. You know, like you're, I don't know, sort of, I don't know, doing something, and you're fully occupied with what you're doing, and something else crops up and it interrupts you and ..//.. it's like that for me with hallucinations. ..//.. It's when I'm fully .... really thinking, and I get interrupted by hallucinations and it affects me. ..//.. So in that way I'd say possibly I couldn't handle doing a full time job, for say, five days a week. I found that I'm up to that stage now where I can do four days, but I have to have one day where it's relatively free, you know. ..//.. We haven't got that endurance that you guys have got, you know? ..//.. Yeah, our brains don't, don't cope with it the same way. Like you'd probably get tired, whereas we'd not only get tired but we'd sort of start hallucinating or ....visually or audially* [sic].
>
> (Liz 3, p. 6)

Michael describes his desire for an easy life, which means one without complications and consequent pressure and stress. The kind of planning which Michael finds he needs to do in carrying out everyday activities is necessary because he finds spontaneous decision-making difficult. Michael also emphasises that his need to plan is more pressing than that of people who do not suffer from an illness such as his.

> *I avoid situations where I find it stressful. So I map out my itinerary for the day ahead. ..//.. When I have to go into town I work out where I'm going to go and which is the easiest way to get there and like driving the car where I'm going to park and I map it all out beforehand so that I don't get into a situation where I have to make up my mind there and then when I'm on the spot. So I've got it all planned out before. ..//.. I think I do that more than other people. I mean people make spontaneous decisions when they get to a situation or to a locality but .... I sort of, I have to plan things out beforehand for peace of mind too, so that I don't get stressed out.*
>
> (Michael 1, p. 16)

For some participants interactions with other people are a source of stress and difficulty. Both Nick and Jack like to spend a lot of time alone. In many situations they avoid other people; Jack sees himself as frightened of others, while Nick has had experiences in which he has felt threatened by others and has found himself in arguments in various communal living situations. Nick describes himself as having settled down as he has grown older and, like Michael, is keen to maintain a quiet life. Nick's major pastimes are watching videos and riding his bike, both solitary activities. As he explained, he uses these activities as a way of avoiding other stressful activities, and as "time out" for himself.

> *Oh I've .... I've changed a bit, eh, I've sort of started to settle down a bit more. I've started to settle down a bit more, you know and ..//.. I like to live a quiet life, eh? ..//.. I don't like too many, too many problems and all that, you know, I don't want to have too many problems and that, you know, and I just like to take it easy, you know, take it easy. ..//.. I would like to get another job though ..//.. and work full time again eh? I would like to work full time again and ..//.. I just like things to be quiet and all, you know, and just take things restful and all that you know, eh?*
>
> (Nick 2, p. 2)

As was mentioned in Chapter Five, Jack understands his illness as being largely one of fear of other people. On the one hand Jack avoids the company of others yet, paradoxically, he also has an extensive circle of friends. One friend had recently committed suicide, and Jack reported having difficulty sleeping as a result: *"I get depressed badly. Loss, you know, loss of friends affects me greatly, I can't sleep at night, .... I don't think very positively...."* (Jack 2, p. 8).

Jack's situation, that of fearing others and yet being intensely affected by his friend's death, is explained to some extent by his description of an over sensitivity to other people's suffering. It is also a good example of *care*; of his focus on caring for others even when he is, or fears being, hurt because of his concern. He has sometimes had friends in hospital and in order to visit them has organised for another friend to come along as a support person. In a subsequent conversation he described a similar arrangement - going with support and sitting near the door so that he could make a quick exit - in order that he could attend a children's Christmas party to which he had been invited.

> *You take on the worries of the bloke next door to you in the next bed, don't you? If you're sympathetic. He's kicking the bucket with cancer or something and you're in there for a broken arm or appendicitis. It's not my cup of tea. I visit people, close friends in the hospital* [general wards], *but I only go down with another close friend that takes me in at night and I visit and if I get crook they get me out to the car before I keel over, you know, which I'm liable to do.*
>
> (Jack 1, p. 14)

The *care* which lies behind the arrangements Jack makes for occasions where he will have to mix with others is reminiscent of that described by Roger, who found it difficult to sit in church (p. 144) as he too was frightened of people and sometimes just wanted to run out of the building.

It is not surprising that Jack reported that his preference for any kind of treatment, should he need it for his mental or physical illness, would be in his own home, in an environment in which he was in charge and where he felt comfortable. Other participants also commented on their desire for home-based treatment if further help should become necessary.

Careful attention to their environment and to recognising situations in which they felt uncomfortable was mentioned by several of the study participants. Some of these references were indirect; Jack talked of his discomfort when a social worker tried to "tidy him up" (p. 151); Lucy of disliking tension in her family home as it made her feel uncomfortable. "*I mean like family life. I like it to be on one even curve, I don't like going all over the place*" (Lucy, 2, p. 34). Lucy described herself as sentimental and liked having her own things around her as this, she said, made her feel secure. Adrian was pleased with his accommodation as his flatmates are "*a quiet living bunch and they conform to my lifestyle really well*'" (Adrian 1, p. 6). The environment may also be monitored for such things as too much noise; Simon's reference to his sensitivity to noise (p. 146) is a reason for his avoiding some social situations in which he finds he is uncomfortable. Parties are distinctly unpleasant for him for this reason:

> *I suspect I was always very sensitive to noises but only became consciously aware of that as a problem more recently. All this about going to parties and so on, and everyone would sit around in close huddle talking like the clappers, and I couldn't hear a word they were saying because there was so much noise.*
> (Simon 1, p. 9)

In order to live comfortably and to avoid further episodes of illness, the study participants developed routines for their everyday lives. Several were keen to make the point that their need for routine was greater than that of people without a schizophrenic illness, and that in some respects they had to plan more carefully than do those without the illness. Each of the participants recognised situations that were stressful and endeavoured to avoid these situations or circumstances whenever it was possible, or to accommodate their own needs in the situation if it was not avoidable.

### Taking prescribed medication and refusing street drugs

As was indicated in Chapter Four, the participants in the study were, on the whole, resigned to their need to take neuroleptic medication in order to control the symptoms of their illness and to prevent relapse. Some participants expressed ambivalence about medication, partly because of its side effects and partly because they felt well and therefore held some doubt as to the need for continued pharmacological help. Judith felt that she ought to be able to control her illness and that medication was simply hiding her problems. At the time of the interview from which this extract is taken Judith had stopped taking her medication for a short time, saying that she could not afford the prescription charges. The reasoning she gives here is rather more complicated:

> *I'm doing all right. Because I know that I've got to face it* [symptoms of her illness]. *I can't hide it. I found that's what I did. It* [medication] *made it go away. I can start seeing, like I'm not seeing things in front of me .... Occasionally I do, but I know it's not real, I know what's real and what's not.*
>
> (What sort of things do you see?)

> *Well I still see shadows occasionally, but I don't let it worry me like I used to. I don't let it control me any more. ..//..*
>
> (So you're saying the medication sort of took you away from what's real? Is that what you're saying?)
>
> *It, what I was seeing and what I was hearing, it was all in my mind. I can see that, it must have been, like something else had taken over, it wasn't me. Because I was always concerned about other people, I was always worried about other people, well now I don't .... I can't let it worry me any more, I've got to think about me, I've got to take care of me. I have to. It's .... I think taking the medication was a way to cover it up. Now I know because I rang the doctor's office, but he's not there, and I said to this girl on the phone, what was going on, and I don't want to be on the medication, because I was a zombie, I was a real mess on it, and I think, why give you a pill, instead of working it out. I don't agree with it eh? I must have .... you know how there's a heaven and a hell? I was in hell. That's how it made me feel. I wasn't living like I should have been living.*
>
> (Judith 3, pp. 5-6)

Subsequently Judith saw her doctor and was prescribed, and tried, an alternative medication which did not have such a sedating effect, but she remained unsure about the wisdom of taking medication as it was "covering up" her problems. Her concern is related to the right thing to do under the circumstances and how she ought to handle her situation which she believes to be much more complicated than simply related to a mental illness.

Liz had been unwell for longer than Judith and was now, as she put it, "committed" to remaining on her medication. However, she did volunteer that coming to this acceptance was a lengthy process, and that she had stopped medication and relapsed before she understood that she did need to take it regularly. Being told about her illness was a critical factor also:

> *The commitment to take medication takes a while to get used to. Because you do go through quite a long time of denial. About everything. ..//.. It depends on whether you get a doctor that will straight-out tell you his opinion or that will say, well we don't really know, they don't really know what causes schizophrenia. So as long as the doctor will come out and give you his or her opinion. To give you something to go on at least. I can remember a little voice saying to me, no. I can remember myself, trying to get an answer, what exactly is schizophrenia, and it wasn't until someone told me it's a chemical imbalance that I started to relate to it. And started accepting it. Up until then they sort of said, well we don't really know what's wrong.*
>
> (Liz 6, p. 10)

Liz's *care* here is about self understanding, guided and verified by her doctor, which then gives her some guidelines as to how to conduct her life and to prevent herself from becoming ill again.

While Judith believed that she should control herself rather than rely on medication to do so, most of the participants in the study had accepted and come to terms with their illness and saw medication as the way to control their symptoms and to prevent a relapse, something of which they were afraid, even if it was thought unlikely.

> *I know that .... if I keep on taking medication and sort of just taking things easy that, keeping my stress levels down and that, it* [acute illness] *shouldn't come back. Well I hope not anyway. But there is a possibility .... there is a fear there in my mind that it could come back and things could be a lot worse and I'm a little bit frightened of what I might do or what I might say. I don't think I'd get violent or anything like that, I think it's just a question of what I might say to people, might put people off. And people running round saying you're mad and all that sort of bloody thing.* (Laughs) *..//.. I think being on the medication is very important. You've got to keep taking the medication to control .... to control your life really, to control the psychosis, keep it at bay.*
>
> (Michael 4, p. 6)

As Michael indicates here, there are several things to be feared in becoming ill. The loss of control which is experienced in a psychotic episode is hinted at when Michael says he does not think he would be violent, while the possible reactions of other people are described as unpleasant and unkind. It is understandable that the participants are *careful* with regard to medication and that most were reliable about taking it. Chris believes one of his drugs helps him maintain control, in contrast to previous experiences of panic attacks:

> *What was constantly in my background was when I was having panic attacks I was .... I had to think ahead "I can't do that, I can't do this" and I was just a total wipeout. And .... but it's not like that now at all. Now that I'm on cogentin all I've got to do is remember to take it. And the moment I forget I know all about it.*
>
> (What happens?)
>
> *Well I start feeling nervous and I suddenly realise .... I realised one day we were north of Auckland, we'd gone on an outing day, I didn't take my pill and I think oh shit and coming back I just go very quiet and I just hang on trying to act normal to look normal and just wait till we get back home and race up to the bedroom and take that pill.*
>
> (Chris 3, p. 12)

The effort Chris describes in "hanging on" and appearing "normal" is intense. It is as though the medication, when he remembers to take it, is able to remove some of his need for concerted effort and attention to his actions. Chris is also concerned to please his mother and to do his best in helping himself by taking his prescribed medication:

> *My mother puts a lot of faith in my treatment and the last time I went off my medication she was saying "Please don't go off, please don't go off" and she was crying right in front of me. That's all she worries about is me going off, and if I did get sick while I was on it she wouldn't hold that against me, she'd be able to accept that, she'd say "Well everyone was doing their best."* (Chris 3, p. 12)

Lucy felt uncomfortable with the sedating effect of her neuroleptic medication, yet understood that it was necessary to keep taking it as she did not want to become unwell again. She frequently mixed together a cocktail of her morning tablets with a drink containing four tablespoons of instant coffee. Lucy's *concern* was to be consistent with her prescribed medication regime, yet also to stay wakeful. The consumption of large doses of caffeine to counteract the drowsiness brought on by haloperidol is an expression of the conflicting dimensions of her *care* in this situation.

In addition to prescribed medication, several of the study participants had had the opportunity to take street drugs, especially cannabis in some form. The younger participants in particular were quite open in talking about this, and about their alcohol consumption. All the participants who had previously smoked cannabis reported that they no longer did so as they found that it brought on symptoms of illness which they wished to avoid.

> *I gave it* [dope] *up 'cos it was ruining my health you know, eh?*
>
> (What was it doing to you?)
>
> *I got too high, you know, and all that. And I started to go a bit silly, you know.*
>
> (Nick 2, p. 6)
>
> *He's got two kilograms of marijuana he keeps in his cupboard* [the reference is to her boyfriend]. *'Cos I used to smoke it and I thought God, that would be tempting. And I thought no, I can't do that, 'cos I don't want to go back to hearing voices. So I keep away from that now.*
>
> (Lucy 3, p. 3)

Giving up street drugs of whatever kind meant a change in social life, and income (there had been some involvement in dealing), for two of the participants. Both of these people felt that their drug use had had a significant part to play in their illness, yet they both also reported that they had had no real help in changing this aspect of their life when they began treatment for their schizophrenic illness.

The amount of alcohol which could be taken by the participants in conjunction with their medication was a matter of their own experimentation, as they described it. Most felt that their capacity to handle alcohol was limited by their medication, but Judith also reported trying *"a few wines"* to see whether any of her symptoms returned. Her experience was that she was not comfortable drinking while taking her pills, another reason why she ceased taking the latter for a time.

The *care* for a life untroubled by further episodes of illness was the main reason for the participants' continued use of prescribed medication in spite of some unpleasant side effects, their avoidance of street drugs, and their moderation in the use of alcohol. None of the participants spoke of coping with their illness, or indeed implied that this was what they had to do. Rather, their efforts were directed toward managing their lives, and in order to live a "normal" existence. Several referred directly to the normality of their lives, as they saw them, as does Roger in this statement: *"Once you can trust the psychiatrist, and are taking your medication as prescribed and at times stated, life is pretty normal."* The *care* for a normal life, in spite of experiences which have been far from ordinary, is a forward-looking one, in which the participants' choices about their lives are goal-directed, yet limited by the way in which they find themselves thrown in-the-world.

### Monitoring thoughts

It is not only actions which study participants felt they needed to regulate carefully if they were to remain well. Several participants also spoke of the need to monitor their thoughts, or to be circumspect regarding the ideas to which they exposed themselves. This is not surprising, given the manner in which participants described being occupied by their thoughts and the element of doubt which has been surfaced as fundamental to the experience of an acute psychotic episode. In Chapter Four several participants described the way that they had to learn which of their thoughts were reliable and which were not. Having once had the realisation of the potential unreliability of their ideas and beliefs they could never be quite certain that they might not again be deceived by their own minds. Television was regarded by several participants as a potential source of danger. Judith worried because she had difficulty in distinguishing what was real from what was simply a story, and had found that the ideas presented on television might precipitate the kind of fears that belonged to her illness:

> *Even different movies on TV..//.. I've got to be careful what I watch on TV 'cos that can spike it off too. ..//.. There was a Dracula movie on TV the other night and I thought, you know, there's none on this planet, we know that, but I mean .... but watching it, it becomes real, you know. If you believe in things like that which were in the zodiac book, you know, because I guess Satan can be caught in so many different forms and all the rest of it, and I sort of think well I shouldn't be watching it because it can still get me in my dreams.*
>
> (Judith 4, p. 12)

The various forms of the supernatural have become mixed together with the devil in Judith's statement here. As she explained, her fears were made more severe by her recent involvement in an alternative church which frequently warned her of the dangers of Satan in his many guises. In Judith's understanding she is not safe even when asleep; ideas she picked up from television might still be able to affect her in her sleep, when she is even less able to exert the control she desires. When there is some doubt about the reality of ideas, then at times dreams may also become suspect, a worry described by Nick who found he sometimes did not know whether the "weird thoughts" in his dreams were true or not.

Michael also avoids some programmes on television, especially those where violence is portrayed. His *concern* is that he might lose control of himself when acutely ill, and then re-enact the things he has seen. This is a particularly frightening concern since, as he explains, the line between illness and healthy judgement is a fine one; it would be possible for him to be ill and not know it.

> *You've got to be careful what you read and .... what you subject yourself to as far as reading goes and watching TV. and .... I mean if you watch violent films on TV all the time you're bound to end up that way in your psychotic episodes and they'll come through in your psychosis and .... you'll start thinking that it's normal and start thinking that it's right and you'll actually do it. ..//.. These things start coming out and you think about things which you'd never think about .... when you're normal. ..//.. It's*

> *a strange feeling. ..//.. Yeah it's .... that's exactly how it .... what happens. It creeps up very slowly and before you realise it you're .... you've crossed that line from ..//.. being normal and going to a psychotic state but the creeping up part of it is done very .... slowly over a period of time ..//.. and all of a sudden it just happens.*
>
> (Michael 6, pp. 12-13)

Liz holds similar feelings about the possibility of becoming overly involved in things she reads or sees on television. As she explains, this is an experience she has had while unwell, and can be a sign of schizophrenia. Although she now considers herself quite well, until recently she has avoided exposure to some distressing elements of the news and current events, for fear of becoming overly affected by them.

> *I get into a book and I start thinking about it and I can be there sort of, actually there when it's happening, not to the extreme, but actually there, playing the part of the person that's onlooking or something. But no I don't get carried away. It's only when I get really sick and I start thinking that I'm an agent* [in a spy story] *or something like that, those are sort of signs for me. If I'm starting to think that way then I'm getting too carried away, or I'm sick or something. It holds you back though, because I've sort of been a bit afraid to get too involved with the newspaper or the Time magazine. Only since the last year have I been watching the news or sort of getting into anything like that because in the past I've got quite carried away. You know, when I've been sick, off medication and that. But they are all the signs of schizophrenia.*
>
> (Liz 5, pp. 8-9)

Judith, Liz and Michael all suggest that the world is sometimes unpredictable, confusing or deceptive. When the world is uncertain there is need for the extra caution and care the participants exercise in their lives. The care explained by these three participants is similar to that implicit in Nick's report (p. 142) of his need to avoid certain people and places because of his experience of unpredictable and frightening behaviour from others.

Several participants expressed fear of losing control and becoming unsafe, although they were also concerned to tell me that they were not, or had never been, violent. In spite of this protestation, some participants were clearly troubled by ideas which had come to them, and which they feared they might act out in a time of diminished responsibility. Jack liked hunting deer in his younger days, and told me how much he would like to take one of his friends up into the bush on a hunting trip:

> *I wished I could go up and take the van up to the country with him, show him all around up in the bush but I can't do it. I wouldn't handle a gun in the bush now, I wouldn't be safe. I used to climb all day with a three nought three* [rifle]. *But I wouldn't handle one now in the bush. Oh it's too dangerous. 'Cos you know, not the way me* [sic] *mentality is. Well I could do anything. When I get crook, if I got crook I'd be able to do anything. If you really, when you get really crook you're .... you've got very, legally speaking, very diminished responsibility.*
>
> (Jack 4, p. 10)

Jack's fear of losing control also related to the possibility that he might harm himself. I asked him directly about suicidal thoughts, during a conversation about the distress which his friend's recent death had caused him.

> (Have you ever thought of suicide?)
>
> *Yeah. Once.*
>
> (Does it frighten you that that ....)
>
> *Could happen? ../.. Yeah. I guard against it. That's why I ring up (hospital) when I start getting crook so I know it's not impossible but technically speaking to happen* [sic].... *That's why I ring them up if I start going all night without sleep. It's available to me, a phone call. Andrea* [night nurse] *is very good. In fact I put a good word in for her down at the hospital amongst the bosses .... to her boss. That she supported me extremely well during the night and .... it was noted on her records.* (Jack 4, p. 28)

As Jack says, he guards against such a thing as a suicide attempt happening. His actions in doing so involve a relationship with a particular nurse, a telephone link he prizes and depends on, since he values the understanding he senses from this woman. Being *careful* in his conduct, Jack seeks help from others who can provide care and solicitude. Living circumspectly means not only monitoring his own thoughts but carefully choosing others whose responses could be expected to be helpful and solicitous. Michael, too, is fearful of his potential for self harm. He relates his thoughts about an action which would result in a kind of accidental suicide:

> *When I'm driving and I see these big trucks coming towards me. ..//.. Just a flick of the wheel and you know .... you'd end up in .... smashed in the front of that truck and ..//.. it really really frightens me that .... just it could happen and .... during a period of psychosis where I don't know it's coming on where I don't know it's happened.*
>
> (Michael 6, pp. 13-14)

The effects of having to monitor their exposure to television, newspapers and magazines, as well as worrying about their potential to lose control in circumstances where they might not know they were doing so, were reported matter-of-factly by the participants. Such monitoring required effort, a vigilance about what was going on and what the ramifications could be, but it had become a part of everyday living for those participants who felt susceptible. Their *concern* was to remain safe and to do so by whatever means they felt were most appropriate, from among the options available to them. In spite of the matter-of-factness with which the participants described their concerns, it is an anxious state of mind which accompanies such concerns. These people fear the potential for lack of control over themselves which lies within their Being-in-the-world, given their situation and their illness.

> Anxiousness as a state-of-mind is a way of Being-in-the-world; that in the face of which we have anxiety is thrown Being-in-the-world; that which we have anxiety about is our potentiality-for-Being-in-the-world. Thus the entire phenomenon of anxiety shows Dasein as factically existing Being-in-the-world.
>
> (Heidegger 1927/1962, p. 235)

Heidegger describes anxiety as a characteristic of Dasein's worldly existence; it is related to the fact of our Being-in-the-world at all, and of our Being-in-the-world in such a way that our existence is an issue for us.

### Managing finances

It would be neither accurate nor adequate to address the theme of **living circumspectly** without some mention of the study participants' need to manage their finances carefully. During the course of data collection I visited each of them in their homes and was able to see their usual living environment as well as to talk about their everyday lives. While all participants lived in accommodation with which they were satisfied at the time of the study, it was clear that for most of them, money was a limited resource which had to be handled with skill.

Only one of the participants in this study held a fulltime job, each of the others being in receipt of an invalid benefit. One held a part-time position and another was supplementing his benefit with part-time work from home, although this was intermittent and I was not able to ascertain how successful his efforts were. While no participant dwelt at length on monetary problems, most reported that they had to be careful with their money, and several did mention the sadness they felt at having to forgo some comforts which they could not afford. At times economising extended to not picking up prescribed medication because of the pharmacy charges. One participant had her electricity disconnected for a time, and several mentioned physical ailments for which they were not able to afford treatment. Adrian has an ongoing "stomach problem" for which he desired, but could not pay for, alternative health care. Liz was trying hard to save up for some dental work and Jack was in need of stronger glasses but had done nothing about seeking them. Financial limitations restricted travel for work or for enjoyment, outings to the cinema or to visit others, and the purchase of clothes, footwear and household furnishings. Of necessity food budgets were meagre for most participants.

> *That's what I mean. The .... a lot of mental patients, a lot of them, the majority, miss out on .... I have never got married, had a family, made a million dollars, toured .... never been out of New Zealand. A lot of me* [sic] *life I've been miserable and*

> *crook, we miss out on a lot of normal living. We miss out. It's taken away from us by society, in a way, because society doesn't .... there's no votes for the politicians in worrying about us. So they're not particularly interested. Not particularly. That's the system. ..//.. Socially and everything. The niceties of life. Yeah, I don't have roast beef. See I love roast beef, see I love ham, I got* [sic] *to budget. Tightly. Tightly. Most of me life I haven't been able to earn money because I've been crook.*
> (Jack 2, p. 17)

Several of the participants spoke of their desire to work in order to improve their financial situation, yet most felt unable to do so by virtue of their illness and its ramifications. The injustices of the social welfare, health and accident compensation systems, along with the lack of understanding of their plight by politicians was cited by several participants, although there also were several who reported their circumstances to be quite comfortable if they were careful, and who felt lucky to be able to draw the benefit which was available to them.

Each of the aspects of **living circumspectly** discussed so far includes some understanding on the part of the participants that their past, present and future are all a part of their Being-in-the-world. It is because of past experiences, incorporated into their way of Being-in-the-world, that they understand what actions they need to take in order to achieve the ends they desire for themselves. It is in this way that temporality is an integral part of *care*. One of the challenges facing the participants in this study is to recall their experiences of illness and treatment and yet also to let them go in moving on with their lives. This is a process which, as the participants describe, occurs over and over again.

## Recalling the Past and Letting it Go

Each of the participants in this study had had the experience of at least one episode of acute schizophrenic illness and each continued to take medication of some kind. This was part of their experience of Being-in-the-world and affected their Being-with-others. **Recalling past experience and letting it go** were important aspects of *care* in several ways. If the diagnosis of schizophrenia was to be integrated into the participants' sense of self then the experiences which had accompanied illness and treatment needed to be recognised and accepted.

However, the *concern* which the participants demonstrated in terms of pursuing a "normal life" also required that they not dwell only with their illness but also look forward and endeavour to make something else of their lives. Several participants spoke of the difficulty they had in persuading others that they were no longer unwell and that they need not be seen as "a patient." It was not only the participants, but family members and health professionals who needed to learn to let go of the past.

There is a fine line to be drawn here. While participants can and do look forward to the future, they can never completely forget the experiences they have had while ill, and indeed they must not; their efforts to maintain their health actually rest on knowledge of their illness. Similarly, coming to terms with lost opportunities in life, and with restrictions and limitations, is done in relation to the facts about what has happened in the past.

> We project ourselves into an anticipated future as the ultimate aim of our endeavours. But this is not the only temporal dimension that is at work in our projection, because our projection is not a free choice of the future. According to Heidegger, we cannot make any such projections without an existing understanding of the world and ourselves in it, an understanding determined by the past we have been and still are. Therefore, not only do we carry our past with us, as one carries weighty memories, but we always already understand ourselves and our projects in terms of the past and out of the past. Finally, in all our enterprises, whatever they may be, we are tied to the present, because we are in and with the world that absorbs us and ties us down to our everyday endeavours.
>
> (Frede, 1993, p. 64)

The terms **recalling** and **letting go** are not synonymous with remembering and forgetting. Rather, they are used to describe the processes by which the participants brought their experiences of the past to mind in the present, and then, as it were put them aside in order to look ahead toward the future. Such a process requires an understanding and an honest appraisal of what has happened, of the participants' own past. "Anticipation of one's uttermost and ownmost possibility is coming back understandingly to one's ownmost 'been'." (Heidegger 1927/1962, p. 373).

Not all of the participants were able to integrate their past and future in this way. Thus the theme, **recalling the past and letting it go**, is not completely applicable to one participant. Adrian was uncertain about acceptance of his diagnosis and was able to relate to only some symptoms of schizophrenic illness, as he understood it. Throughout the interviews I had with him Adrian was keen to talk about the present and about his future plans, but preferred not to talk about his time in hospital, or about the nature of his illness. Adrian's situation will be discussed further in the next chapter.

As was discussed in Chapter Five, many people with a schizophrenic illness find it difficult to talk to others about their experience, since they are unsure of the reaction with which they will be met. There may well be some who simply forget what the experience of an acute episode of psychotic illness was like.

Simon has done considerable study into aspects of schizophrenia. He felt, from his experience of illness, that he would have benefited from some kind of educative, supportive psychotherapy during the period in which he was recovering from his illness. He suggests that people who have a schizophrenic illness need help in understanding what has happened to them, if they are to integrate their experience into their lives as a whole. Simon explains that the psychotherapy he envisages is not that commonly recognised as encouraging insight at a subconscious level, but rather one which would serve an integrating function:

> *The word psychotherapy usually .... although it commonly means people should look into their subconscious and get some insight into what was controlling them, their behaviours at an unconscious level and I don't think that is appropriate because I think people with schizophrenia have more capacity for looking inwards than most people and I think that is possibly to their detriment .... but the things that go on in a .... let's talk about an acute psychotic breakdown, not the chronic impairment, but in an acute psychotic breakdown, say occurring to someone at the age of twenty. They have not enough understanding of human psychology to know what on earth has happened to them. They don't have a framework of concepts to start to rebuild it and I think it is possible with using psychological terms translated into everyday language it would be possible to explain .... give*

> *those people some sort of framework for understanding what has happened to them. ..//.. I think there are some research findings that say that people who encapsulate their psychotic experiences so that they can't think about them and access them by their memory don't do so well as those that integrate their psychotic experiences into all their other experiences. Which is perhaps what I am suggesting that one could help to integrate those psychotic experiences without forgetting them. On the other hand there might be some people who might be better just to forget the whole thing if it has been a very quick recovery.*
> (Simon 2, pp. 6-7)

Liz is quite clear that she has a schizophrenic illness. However, as she explains, although it is an acknowledged part of her life, it has not been easy to come to terms with the illness. Some of this difficulty relates to her reading several books on the subject of schizophrenia which, in Liz's opinion, discuss prognosis too pessimistically. She particularly mentioned Andreasen's (1984) work in this regard. In contrast to what she sees as a less than hopeful future described in some of the literature, Liz has been told by her doctor that her illness has helped her mature. Here Liz explains how she has tried to come to terms with her illness:

> *I don't know if you ever do really. You make the most of it. Of the quality of life you've got at the moment, but I don't think you ever come to terms with it, really, I don't know .... You just go on each day, each day or each week or each month, and make plans, and hope for the best, and try your hardest. And make whatever's going on work out right. And its the same with your illness, you know, you can't predict stress levels everywhere you go, there's always going to be some stress somewhere, you know, and not just good stress, you know, sometimes really bad stress. And you can't, I mean you can walk out or you can do .... there is* [sic] *certain things that you can do, but .... in a way you're sort of walking out on part of your life, part of your experiences, you know. And schizophrenia is one of my experiences, and like the doctor says, the schizophrenia is good for my character* (laughs), *so in a way I should be lucky I've got it, if I listen to him. Which I do.* (Liz 4, pp. 14-15)

The effect of past experience and of the way that the participants found themselves in-the-world was sometimes very difficult. Chris is philosophical about his illness and accepting of his diagnosis, yet as he explains, there are times when life looks very dismal to him.

> *It's hard being paranoid. It's not hard being high but it's hard being paranoid. And it's hard being schizophrenic because you are not part of society any more, you haven't got a job .... you're not at university any more, you've got nothing left. Other people who I would think of as having a hard life are people who appear to be very brutish and whose only enjoyment appears to be drinking and who work like dogs to .... what appears to me to be like they work like dogs all their lives, but they wouldn't feel like that, they'd feel on top of the world I think. But you don't feel like that when you are a schizophrenic. There's no thing of, oh OK you can feel on top of the world when you are on a high, but when you are not on a high .... you are at the bottom. And .... and as much as schizophrenia can give great imaginative things, but* [sic] *it can also take all your imagination away and leave you with .... with just rock hard reality. No comforting job, no comforting relationships, no comforting anything. ..//.. It is out of control, it is something that just happens. You get to the stage where you're thirty .... you feel like you've accomplished nothing, you're just walking down the street and that's all you are doing .... you're not thinking, you're not planning, you're not looking forward to anything, you're just walking down the bloody street. It gets a bit tiresome after a while.*
>
> (Chris 3, pp. 23-24)

Not all the consequences of having a schizophrenic illness are negative ones. Several participants were able to find positive aspects in their experience, and to identify strengths or opportunities which had arisen for them as a result of their life situation. Chris likes to write and to draw cartoons, while Simon has also written about his experiences. Chris finds much of his inspiration has come from the ideas he had while unwell. Lucy, similarly, found that she was able to paint most productively when she was recovering from an acute illness. These participants were able to capitalise on the process of recalling the past, incorporating their recall into their creative projects.

> *When you are ill you're thinking .... when you're on a high you do nothing but think. Think, think, think. And then they take you off the high and you've still got all those things that happened to you on the high that you've got to sort out and file and categorise and stuff and you can think about what, what .... you can think about your last illness for the following ten years, all the thoughts that occurred to you.*
>
> (Because you had so many or because you have to make sense of them?)
>
> *Well, because they were so amazing at the time. They felt so amazing, and they were so amazing that they were so unique and individual. ..//.. if you've been high you know what it is to be totally original and totally unique and the thoughts there that happened to you, no one else can know about them only you can deal with them. And like I write novels based on the thoughts that happened to me.*
>
> (Chris 3, pp. 22-23)

While thoughts such as those mentioned by Chris were useful, tantalising and retained, there were specific, frightening or unpleasant aspects of illness which participants felt it best to let go of. Lucy kept a diary during some of the time she was most unwell. She describes how and why she decided to destroy this evidence which was a reminder of her illness. In particular she felt that in order to move forward with her life she needed to be rid of the voices which had directed so many of her actions:

> *I had to record the next sighting of whatever I saw. Because I had everything in exact detail. And in March this year I just got so scared and I thought oh shit, I can't keep this, 'cos it was so painful looking back. And it was like I was reliving it. And I thought if I'm ever going to break free from it I'll have to burn them I'm afraid. Now it's a good way for me getting rid of them.* (Lucy 2, p. 20)

While people who have had an acute schizophrenic episode may be able to let go of the notion that they are unwell, to recognise that they are recovering and to wish to continue with their lives in as normal a way as possible, it is sometimes difficult for family members to stop worrying about relapse. Lucy lived at home with her parents and on several occasions has observed her family over-react, as she sees it, to what she considers normal demonstrations of emotion. As she explains, she actually welcomes being treated as someone who is well so that a row with her parents becomes cause for relief.

> *They just don't believe me. And I cried the other day. And they went and hid my pills. They thought I was going to take an overdose. And I just can't put up with that. But I know they're starting to believe it or accept it, that I'm doing so well. Then they get angry with me. And I can get angry back. They actually lose their temper with me sometimes. And I can have a good yell. And I think oh great, great.*
>
> (Lucy 2, pp. 10-11)

> *Yeah. Well what I'm trying to tell you is how bad it was before and how good it is now. ../.. Now I pull the curtains back and .... I'll think God it's good to be alive. And I do it. I've been doing it since January. And oh it's worse when I start singing Oh What a Wonderful Day. And I make up songs, the sun is shining and all this shit. And mum really starts to worry then. She, I think she worries more now than she did before. She thinks "What's going on here ?"* [in her head].
>
> (Lucy 2, p. 31)

Liz has found a similar reaction to that of Lucy's parents, this time from her nurse, whom she believes has not allowed her any leeway for the normal anxiety and distress which accompany life events - in this case a job interview and a death in the family. The result is a lack of trust between them. Liz worries that if she asks for advice from her nurse she may be seen to be vulnerable and close to breakdown. Instead she refrains from talking many things over, preferring to solve as many of her problems as she can on her own. Liz interprets her nurse as having trouble letting go of the patient she has known Liz to be. I asked Liz who she uses for advice when she has problems.

> *If anything sort of health-wise for myself is happening then I ask my nurse straight away. But then she tends to over-react. Because there was a situation last year where there was a death in the family and I was going through a job interview all in the same day. And I got quite anxious, and I told her about it afterwards and I heard back from my doctor that I almost had a breakdown. But it wasn't that bad. I was anxious for half an hour, it was uncontrollable anxious* [sic], *it was really horrible, horrible feeling. But she's actually said to the doctor that I had a break down, almost had a breakdown, bordering on a breakdown, so I was quite pissed off. But anyway, at least that stopped them from lowering my medication again. ..//.. You know, life had been really boring, nothing had been happening. ..//.. Yeah, but I keep as much to myself as I can. Until I've got it worked out and thought through, until I'm happy with it.*
>
> (Liz 5, p. 9)

Roger's faith in God is a comfort to him in his recalling the past and letting it go. He frequently reviews his life, back to the difficulties he believes he had with his mother when he was a baby. In addition to his schizophrenic illness, Roger thus deals with a perceived lack of love from his family, and has also had to deal with congenital abnormalities which have lead to surgery, and to ongoing degenerative difficulties in his later years. That he goes on with his life in spite of his losses he attributes in part to his faith, and the belief that someone is watching over him. Roger believes that he has been held back in his progress by some ten years or so, as a result of his illness:

> *Well even though I'm 42 I'm still acting as though I'm about a 30-odd year old sort of thing, you know, and because I've, I don't know, I should be in life properly now, I should have teenage bloody kids, actually.*
>
> (Roger 3, p. 4)

The reconciliation of the fact of having been ill, of some residual difficulties, and of the now altered future experienced after coming to terms with Being-in-the-world in this way is summed up in Judith's statement, below. She talks of the way she has now to reconceptualise the future, as a result of the cumulative effects of some physical trauma and the experience of schizophrenic illness.

> *But as far as myself is concerned, I can see now that I'm not the person that I used to be. And it's hard to handle. And you think what else is going to happen? I sort of thought well, I'm really fighting hard to figure out what I'm able to do, and where I'm going to go from here. And what's in store for me, in my future.*
>
> (Judith 3, p. 1)

> *It's wrecked so many things for me. Because I really want to succeed in doing something. I know I can do that, but I don't know how to go about that. I don't know what steps to take. It's like the sun setting in front of me, and I'm going to go for it, but I know that there's going to be a lot of set backs on the way.*
>
> (Judith 3, p. 4)

The *care* expressed here is for the mapping out of a future life, for finding something satisfying and productive to do, and for discovering how such goals might be achieved. These concerns are among the aspects of *care* to be discussed in the following chapter, in which the themes of **holding onto hopes and dreams,** and **taking a stand on life** are explored.

## REVIEW AND SUMMARY

In this chapter the everyday choices and actions of the study participants were introduced and discussed as they relate to Heidegger's (1927/1962) notion of care *(Sorge)*. *Care* "designates the basic feature in us that constitutes all our involvements in the world" (Frede, 1993, p. 63). The choices made in everyday living relate to the participants' Being-in-the-world and their Being-with-others. It is out of their experience of illness and treatment that some choices become more urgent than others in the everyday lives of participants. The *care* which participants took in their everyday actions has been described in the theme **living circumspectly**, which included regulating and monitoring actions, environment and thoughts. Participants were *careful* to avoid stress and to maintain a routine in daily life, in as much as this was possible, in order to avoid further illness, and to maintain their own comfort level in the world.

The need to manage finances carefully because of a limited income was apparent for those participants who were not working, and in turn limited the choices and possibilities open to them.

A further aspect of *care*, demonstrated and described by the study participants, is its temporal dimension. Understanding and accepting the nature of their illness, and recognising that care is needed in managing their lives from here on has enabled most of the participants to integrate their past into their present. They are able to **recall their past**, to recognise and come to terms with that experience and to **let it go.** They avoid dwelling with their illness or in the past, yet to continue on with life in the light of the understanding they have from these experiences, which are part of who they are in-the-world. In Heidegger's terms, Dasein is its own "been." It is not only the participants themselves who must let go; in their experience they also find that family and health professionals must learn to accept them as no longer unwell, and to let go of the "patient" or "sick" ways in which they were previously known.

According to Heidegger's description of human existence, to know what we *are* is at the same time to know what we *can and should be* if we are to achieve coherence and unity in our lives (Guignon, 1993, p. 231). In integrating their experiences of illness and treatment, their Being-in-the-world and Being-with-others, participants also looked forward to the future; they were concerned in their involvements in the world in a future-oriented way. All actions and choices are for-the-sake-of some end. This aspect of *care*, the making of a life which adds up to something, is discussed in detail in the following chapter.

# CHAPTER SEVEN

# TAKING A STAND ON LIFE

## Introduction

In this chapter Heidegger's notion of *care*, introduced in the previous chapter, is extended and elaborated. In Chapter Six the dimension of care which relates to the everyday actions of the study participants was discussed. In this chapter *care* is shown to encompass the way in which the everyday actions and choices of the participants are directed toward the living of a life which, for each of them, has meaning, which adds up to something. Two themes which were identified in the data are presented and discussed in this light: **holding on to hopes and dreams** and **taking a stand on life**. The latter, from which the title of this chapter is drawn, is related to Heidegger's notion of taking a stand, and his discussion of authentic and inauthentic modes of Being. The relationship between care and temporality has already been mentioned in Chapter Six, and will be extended in the discussion in this chapter.

"Heidegger describes human existence as a 'happening', a life story unfolding 'between birth and death' " (Guignon, 1993, p. 8). It is through the actions and choices in which we engage ourselves in everyday activity during this "temporal unfolding" as Guignon calls it, that we come to constitute ourselves, to make something of our lives. In making choices we have available to us some predetermined, culturally bound alternatives. The process of making such choices is referred to in Heidegger's (1927/1962) work as *understanding*.

> By "understanding" Heidegger means literally taking a stand on. We take a stand on our own being whenever we choose a particular possibility or project. Every purposive, future-directed choice from among the culturally determined alternative possibilities expresses an understanding, in Heidegger's sense, of what it is to be a human being.
>
> (Hall, 1993, p. 137)

It is as a result of making choices from among the available alternatives that we become what we are, that our lives will be seen, at their end, to have had a particular configuration, direction, and purpose. "Because our lives matter to us -

because who we are is 'at issue' or 'at stake' for us - we always take some stand on specific roles and self-interpretations in living out our lives" (Guignon 1984, p. 331).

The choices we make, however, need not be consciously thought through; indeed it is a central premise of Heidegger's work that it is in everyday, pre-reflective activity that the nature of Being of Dasein is to be found. Ultimately our lives are defined by the stand we take in making our own choices in life, whether or not we make them consciously.

> Since *who* and *what* I am is defined by the actual roles I take over in making choices for my life, my Being is defined by the goal-directedness with which I take up pre-given possibilities in dealing with the current situation. This structure of Dasein as a thrown projection that is engaged in the world makes up the formal definition of "care," and its "ontological meaning" is found in the "temporalizing" (literally "bringing to fruition") of temporality. Because each of us is solely responsible for what his or her life adds up to "in the end," Heidegger says that Dasein is "in each case mine." No one can fill in for me in the project of making something of my life as a totality.
>
> (Guignon, 1984, p. 332)

Because this chapter deals with the stand that the participants take on their own lives it is here, more than in any of the previous three data chapters, that their individuality is most clearly demonstrated. While some facets are held in common, no one person holds the same constellation of values, aims, hopes or ambitions. One of the most striking attributes of the participants was their individual courage, their determination to get on with their lives in spite of distressing experiences and the effects of stigma associated with mental illness. Each of them was engaged in the world in his or her own way, making plans and maintaining a personal moral stance toward their way of Being-in-the-world.

Each of the participants could be said to be hopeful, in that they had a positive outlook on life and looked toward the future, yet not all voiced specific hopes or dreams. In part this is unsurprising, in that it is in their everyday lives that people carry out their plans, anticipating the future as they do so. However, closer examination of the data revealed that all participants were, in fact, living with hopes for the future, even if these were not emphasised in conversation, or were referred to only obliquely. As Steiner (1978, p. 98) explains, in Heidegger's analysis "Desire and hope are the reaching-forward of care." In **holding on to hopes and dreams** the participants maintained a hopeful state-of-mind and held up for themselves goals for which to strive and dreams to which they felt they could aspire.

### Holding on to Hopes and Dreams

In "Being and Time" Heidegger is clear that hope is not simply a forward looking expectation. Rather, hope is intensely bound to past experiences. Hope, he suggests, is related to our "having-been," to past hurts, disappointments and pain. As the opposite of "depressing misgivings" hope is possible only when the past is acknowledged and taken on board. Hope is related to what we wish and look forward to for ourselves. In order to look forward in this way we must acknowledge what has already been and accept our thrownness, the way we are in-the-world. It is only from this acceptance that we can move forward to what we hope for. Hope, as futural, is thus also tied to the past and to the nature of Dasein as aware of itself. The following quote, while abstruse, contains ideas which are highly relevant to the discussion which follows. Examples from, and reflection on, the data will explicate the points the reader is asked to consider.

> Hope has sometimes been characterised as the expectation of a *bonum futurum*, to distinguish it from fear, which relates to a *malum futurum*. But what is decisive for the structure of hope as a phenomenon, is not so much the "futural" character of that *to which* it relates itself but rather the existential meaning of *hoping itself*. Even here its character as a mood lies primarily in hoping as *hoping for something for oneself*. He who hopes takes himself *with* him into his hope, as it were, and brings himself up against what he hopes for. But this presupposes that he has somehow arrived at himself. To say that hope *brings alleviation* from depressing misgivings, means merely that even hope, as a state-of-mind, is still related to our burdens, and related in the mode of *Being*-as-having-been. Such a mood of elation - or better, one which elates - is ontologically possible

> only if Dasein has an ecstatico-temporal relation to the thrown ground of itself.
>
> (Heidegger 1927/1962, pp. 395-396)

The different life situations of the participants meant that there were different aspects of life which called for hope. Those participants who were in stable relationships, for instance, had no need of hope in regard to their locating a partner in the way that several of the unattached people did. Those with children all held hopes for them in the future, even if they were very broad and unspecific hopes.

Most hopes expressed by the participants related to living a "normal" life. Those who lived in supervised accommodation spoke of a desire to live with "ordinary" people, or to own a house of his or her own. Liz and her fiance lived in a small council flat in a supervised block; Liz hoped that they might eventually be able to rent on the open market and thus escape the welfare system in that regard.

Given their circumstances and the manifestation of their illness, it might look unlikely to an outsider that Adrian or Nick would be capable of living in unsupervised accommodation. However, each had a dream of the house he would like eventually to own, and the life which would accompany this. Adrian would like to own and run his own business in one of New Zealand's larger cities. His hopes for a house of his own are quite specific:

> *I'd like a three or four bedroom place, and a kitchen, dining room, lounge, bathroom, toilet, all for about a hundred and twenty thousand* [dollars], *I think I should be able to afford that. If I can make good money at the job down there I should be able to afford it all right. It would be a wonderful investment.*
>
> (Adrian 2, p. 10)

As Adrian explains, he would also like a wife and family. He gave an example of a family member who did not have children until she was older than he is now as proof that there is still time for him to achieve this goal. Adrian does not currently have a girlfriend, and although he has not had "*much success in that area in the past*" he is sure that he will meet a suitable partner "*sooner or later.*" Nick, too, dreams of his own home (house, flat or unit), work, a wife and family. The wife he has in mind is identified as a young woman he met several years ago while overseas. In Nick's mind there is still a possibility that this relationship might be rekindled. His holding on to this dream in spite of his loneliness and isolation, and in the face of little in the way of reinforcement, reflects Heidegger's position that hope is tied to our burdens. Nick's aspirations in regard to this young woman featured in each of the visits I had with him during the course of data collection.

> *I'd like to work on a dairy farm or .... dairy factory, eh? ..//.. yeah, I'd like to work on a dairy farm or that you know and .... I wouldn't mind being a dairy farmer myself actually, eh? You know I wouldn't mind milking cows and that you know and doing dairy farm, dairy farm work, you know eh? ..//.. I'd like to get married one day and have kids like, you know, I'd like to get married and have kids and all that you know. And perhaps be a father to some children or whatever, you know, eh? Have a wife and kids and all that you know, eh? ..//.. I did like Hannah, that's the girl I really liked. I met her .... she's .... I did like her and she was she was very nice to me and you know and she seemed to understand me quite well you know and all that and .... so I guess I'm quite fond of her you know, eh? ..//.. me and her sort of had this sort of special thing you know eh?*
>
> (Nick 1, p. 8)

In discussing his hopes for work and a different living situation from his current one, Chris was clear that many of the things he hoped for also depended on other achievements. Work, finances, activity and social skills were all described as being interrelated. His statement, below, illustrates the way in which he held on to a hope that things would improve and that he would be able to meet each of the challenges he identified. His hoping is not idle; rather his statement shows how interwoven his hopes are with his fears and his past experiences. Here Chris is talking of his recent visit to Workbridge, an organisation which specialises in finding employment for people with disabilities.

> *I've contacted Workbridge again and so we're talking about work experience there again and she's talking about a job in a bookshop.*
>
> (Would you like that?)

> *I don't know, I'd have to try it. I'd like to get into a job and have .... and occupy my time and save up money and stuff like that and I'd like to move into another flatting situation with ordinary people but I'd have to be set up first and I'd have to have an activity during the day before I could move into a house away from here because otherwise I'd be sitting around all the time and that's not much fun. Although in the past when I've had a job I just loved the thought of just being at home and doing nothing. But I think this time I'd be able to handle a job better and actually enjoy my work. That's what I'm hoping will happen.*
>
> (Chris 2, p. 12)

Achievement in a field which interested them was the subject of the hopes and dreams of several participants. Here, as in the dreams about home and family life, some of the hopes of the participants seem grandiose and unlikely to be fulfilled. However, whether or not the dream is attainable is not really important in terms of its function as a counter to a sad and difficult past and present, as Heidegger suggests hoping to be. Liz would like to train as a teacher sometime in the future, but she fears that her illness may preclude this as a possibility for her. As long as she leaves this aspiration at the level of a future hope she has something positive to look forward to. It may well be that she does not seek the answer to her question for fear of what that answer will be; certainly in this statement it does not appear to be something which is of pressing urgency for her.

> *I'd like to go back to school, but I don't know, sometime, at some stage. My Dad's a teacher, so I'd sort of like to do .... I wouldn't mind doing something like that, but then I heard that .... I've got to find out for myself, but that you weren't allowed to be .... get into the studies if you had mental illness. I don't know if that's true or not.*
>
> (Liz 1, p. 9)

Adrian sometimes contemplates going to university to study toward a business degree. While he enjoys the idea of gaining his degree, he feels that this is not the right time to begin because of the amount of work involved. As will be discussed later, this hope is congruent with the stand Adrian is taking on his life, in his enrolling for several short courses at a local educational institution. The degree fits into his future; it is both an aspiration and a comfort to think that he could achieve in this regard.

Jack places a great deal of trust in science and education. Not having been in a position to gain much formal education in his youth, he now dreams of leaving money for an Institute of Higher Learning, which would include social, medical and scientific research. The Institute would be named after him, and would carry on *"for all eternity."* Given Jack's concern for the environment, politics and science, his dream might be seen to cover both his desire to do good in the world, and to make possible some recognition of his worth and personal contribution.

Chris became ill while he was a university student and subsequently had to withdraw from his studies. He, too, holds a grandiose dream about recognition, this time for his intelligence and problem solving ability and his personal moral stance:

> *This is another thing, a personal thing .... I think that I might be as important as Einstein because when I was at university the first time I came up with a legal argument in a Privy Council case that had never been thought of before by anyone. And then I did another assignment which I think was pretty much on the same level but I never went back to collect it because I had achieved everything with my third assignment and I didn't want anyone to say that I got less than an A. I just couldn't handle that any more, having some idiot tell me what I'd got; I thought I'd reached a stage .... I had reached a stage where I was not prepared to listen to other people's evaluation of my work. And I like to think that I did something there that was taken notice of and of course I wasn't interested in any reward for it or anything. I like to think that it became important that it was important ..//.. and now I like to daydream that it was as important as the theory of relativity or more important so now I'm walking around everywhere thinking I'm as good as Einstein.* (Laughs). *And in some ways I think I'm better. He had a son who was in a mental hospital and he did something to his first wife which wasn't very nice, divorced her or something, and never went to see the son. I don't know, something like*

> *that. But he wasn't perfectly good, this is from his .... one of his other children, they were saying he wasn't God you know. And that people have this image of him as being totally incorruptible and everything when he was as corrupt as most people. And I'm not.* (Laughs).
>
> (Chris 3, pp. 21-22)

In this interview Chris's laughter demonstrated the amusement he felt at holding such dreams, which he acknowledged to be far-fetched, yet the solace they provide in the context of his past life is also poignantly apparent.

Two participants, Liz and Jack, held out hopes for a cure for their illness, although both suggested that this may not be in the immediate future. Jack's faith in scientific discovery is demonstrated in this passage, in which he describes his belief in a cure, and also even in an end to ageing and to death:

> *Well one of the .... one of the things that gives me something to hang on to .... see I believe that sooner or later no-one will die. Old age is a disease, an illness. It is quite possible in both our lifetimes* [his and mine] .... *I've told you that the next twenty years is going to see more advance in medicine than has happened in the last two thousand. Well if you get cancer in say ten years, or heart trouble or stroke or start to age, most of them will be reversible. All of them will be reversible. That's something to hang on to. That gives me something to hang on to. Someone might come up with a total cure for .... my .... my condition. See you got to* [sic] *hang on to something and that's one of the things I hang on to. That sort of knowledge. ..//.. After all we're just a chemical .... we're .... presumably we've got a soul or a spirit of some kind, but we are chemical matter are we not? ..//.. Chemical matter. Well matter's indestructible. It .... just alters its form. So .... they'll give you an injection you name what you want to be, twenty, thirty, forty, or ten or .... you know, it will be technically possible. ..//.. I don't like the thought of being dead for ever. Just dust for all eternity. Dying as such if I was going to come to life again in six months wouldn't worry me. Be a nice .... little holiday. But if we're going to be dead for ever which I don't think it has to*

> *happen* [sic]. *..//.. you know it's possible to avoid that. So that's one of the things I hang on to.*
>
> (Jack 4, pp. 18-19)

Jack's use of the term "something to hang on to" is a clue to the usefulness of hopes and dreams such as he holds. It is through forward looking hopes that he is able to provide himself with optimistic, positive thoughts. Since his mind is often occupied by the frightening experiences he has had in the past and the way he believes that his experiences in hospital more than forty years ago have ruined his life, the comforting nature of hoping may well provide the life-raft he alludes to. There is a problem in Jack's belief in science, however, whose irony he was keen to point out. He has several friends who are Christian and believe in the dates provided by the church as to the time of Adam and Eve. Such dates are not compatible with those suggested by palaeontologists or astronomers regarding the age of the earth, universe and dinosaurs. Jack's fascination with evolution and its incompatibility, as he sees it, with religion, was a frequent source of conversation during my interviews with him. If science could not conquer death, perhaps religion would provide the answer. Jack's solution was to attempt to believe in the creation story, and to pray. As he put it:

> *I worry about death, being dead, because I'm not sure whether there's a heaven or whether we are just dust for all eternity. ..//.. You hope and wish don't you there is a heaven. ..//.. I pray now because you've got to hang on to something.*
>
> (Jack 2, p. 8)

Spiritual ideas, whether in orthodox religious form or contained in some personally constructed belief, were important to many of the participants. They served both as a source of comfort and as a means of organising values and actions. Chris explained that he had thoughts which comforted him; these include the previously mentioned ideas about himself and Einstein, which he acknowledges to be grandiose. To have comforting thoughts available to them could be seen as a necessity for people who continue working at their lives in spite of the difficulties which illness, treatment and consequent social isolation and impoverishment has meant for many of them. As Chris said on one occasion:

> *Even from day to day, you've got to* [have something to look forward to] *..//.. and quite often I don't have anything to look forward to. ..//.. Things to look forward to like meeting someone, that .... you know, going out with someone, or going to a party or doing some activity that you like doing.*
>
> (Chris 3, p. 14)

Under the heading of **hopes and dreams** in this section, discussion has ranged across a spectrum of possibilities in the minds of the participants. Pure and unambiguous definitions which would differentiate between hopes, dreams, wishes, faith and beliefs would be neither possible nor useful in a study such as this, which concentrates on the life stories of the participants. It would be artificial to divide the participants' aspirations into those which are "realistic" and those which are "delusional" or "grandiose." While such divisions may form a useful part of an interview designed to gather information for the purposes of diagnosis and treatment, in the life stories of people who are to all intents and purposes well, as were the study participants, of necessity any such categorisation would mean losing sight of their imaginative, creative and meaningful nature. There is also the potential of abusing the honest communication in which the participants shared some of their most unusual thoughts. Most people probably nurture dreams or fantasies of fame or wealth in some form, for example, yet are not in a position to have such ideas diagnosed or judged as to their feasibility. By whatever names the thoughts and dreams of the participants are known, they serve a clear purpose of directing the participants into the future, a future which can be seen in a positive light whatever their past experiences might have been. As such they form part of the background and context to the stand which the participants take on their lives.

### Taking a Stand on One's Life

As Heidegger (1927/1962) explains, it is in taking a stand on life that we come to shape ourselves, to mould the configuration and pattern that our life will show itself to have been "in the end." Taking a stand involves the way in which we "press forward," or "project" ourselves into the possibilities which are available to us. Every choice made in day to day activities forms part of this taking a stand.

> Dasein's "being" or personal identity is defined by the stands it takes in acting in day-to-day situations over the course of its lifetime. Heidegger expresses this by saying that Dasein is an "ability-to-be," which comes to realisation only through the ways it is channelled into concrete "possibilities," that is, into specific roles, relationships, personality traits, lifestyles, and so on, as these have been made accessible in its cultural context.
>
> (Guignon, 1993, p. 9)

Most of the time we do not make such choices conscious of their ultimate significance. We simply carry on with everyday life at an everyday level. At the same time, for the most part the possibilities from which we chose are limited to those which fall into the realm of public understanding. One simply does what "one does" in a given situation. The nature of everyday Being-in-the-world is one which is engaged with others, and which is culturally and historically bound. In Chapter Five Heidegger's term *falling* was introduced. Falling is the tendency for all of us to act in the way that "one does" in our particular social and cultural context. At least temporarily, in falling we lose sight of ourselves as unique, individual Dasein. Although we are our own potentiality-to-be, we become "lost" in the ways of Being which are common also to the Others. Much of the time we do not act responsibly in choosing our everyday actions, nor do we realise that we are not doing so.

> As thrown, Dasein has indeed been delivered over to itself and to its potentiality-for-Being, but as *Being-in-the-world.* As thrown, it has been submitted to a "world," and exists factically with Others. Proximally and for the most part the Self is lost in the "they." It understands itself in terms of those possibilities of existence which "circulate" in the "average" public way of interpreting Dasein today.
>
> (Heidegger, 1927/1962, p. 435)

This ordinary everyday way of being-in-the-world is characterised by Heidegger as belonging to either the undifferentiated or the inauthentic mode of existence. We exist in the undifferentiated mode when we make choices unconsciously (Hall, 1993), while in the inauthentic mode, we are concerned and absorbed with fitting in with others *(das Man,* or *the they).* The alternative mode, authentic existence, is possible when we come face to face with the realisation that we will eventually die, that we are in fact Being-toward-death. Such a realisation creates **anxiety** in Heidegger's terms, and in the face of such realisation we are likely to wish to flee. The place to which we flee is back into the comforting, reassuring world of the "they" (Hoffman, 1993). The authentic stance requires facing up to the ultimate nothingness which we will become; acknowledging the certainty of our own death and resolving to live our lives in a way which we believe will enable us to "become what we are" (Hoy, 1993, p. 180).

As Guignon (1984) points out, the authenticity of which Heidegger writes is not the same concept as that commonly found in some recent populist "existentialist" literature. Heidegger's concept is neither one which is simply a matter of being true to one's own inner feelings, needs and drives, nor a solely individualistic one. Rather, "Heidegger's emphasis [is] on involvement in the world as constitutive of the self" (Guignon, 1984, p. 322), and relates to the historical understanding of an entire culture. In addition, the authentic mode of existence is not one which can be sustained continually. Rather, each of us is likely to fluctuate back and forth between authentic and inauthentic modes of Being. "As he [Heidegger] repeatedly affirms, there is no way to live permanently in authenticity, since we have to take the everyday world and its routine for granted in all our practical concerns" (Frede 1993, p. 57).

Neither is the concept of inauthenticity meant to signify any less valid mode of existence than is authenticity:

> As modes of Being, *authenticity* and *inauthenticity* .... are both grounded in the fact that any Dasein whatsoever is characterised by mineness. But the inauthenticity of Dasein does not signify any "less" Being or any "lower" degree of Being. Rather it is the case that even in its fullest concretion Dasein can be characterised by inauthenticity - when busy, when excited, when interested, when ready for enjoyment.
>
> (Heidegger 1927/1962, p. 68)

Using examples from everyday life, Guignon (1993) explains that the authentic mode can be likened to a "constituent-ends" approach, in contrast to a "means-ends" approach to life. In the constituent-ends approach to life choices are a conscious part of realising our lives as a totality over which we have some control.

> Here actions are not just routes to achieving extrinsic ends, but instead are experienced as central to *constituting* a particular way of life, a way of life that is good *because* it consists of this and comparable sorts of activities. Action here is undertaken *for the sake of being* such and such: I run as a part of being a healthy person, or I help someone for the sake of being a good friend.
>
> (Guignon, 1993, p. 230)

As has already been suggested, the experience of mental illness means re-examining who one is in the world. The experience of mental illness, for all but one of the study participants, has been such that it has forced them up against the anxiety of which Heidegger writes and has resulted in an acknowledgment of the frailness and finitude of human existence which anxiety entails. The one participant who did not fully accept his diagnosis and who chose not to speak about his illness is an interesting instance; in fact it could well be postulated that he is living mainly in the inauthentic mode, having fled from the anxiety which his illness experience has actually precipitated.

As has been detailed in Chapters Four and Five, the study participants found that experiences of illness and treatment have a significant impact on their Being-in-the-world, while they live in a world in which their Being-with-others is often problematic. Several participants were keenly aware of some of the ironies and inconsistencies in the social world and much of their humour reflected this understanding. The profound nature of many of the statements quoted in the data chapters of this thesis are also testimony to the way in which the lives of the participants are not taken lightly. As Simon worded it, he often found himself "on a level of seriousness" which frightened most people. The recognition of our need to face up to our lives as they are is part of the challenge of authenticity.

> Once one has grasped the finitude of one's existence, it snatches one back from the endless multiplicity of possibilities which offer themselves as closest to one - those of comfortableness, shirking, and taking things lightly - and brings Dasein into the simplicity of its *fate*.
>
> (Heidegger, 1927/1962, p. 435)

One of the distressing elements of their fate recognised by the study participants is their difference and distance from the anonymous *they*. Such distance may be measured in two ways. Firstly, by virtue of the experiences encountered in illness and treatment and in their ongoing lives, the participants, on the whole, recognised that they were in some ways not the same as most other people. Their experiences are not shared by the general populace, while many aspects of the *care* they need to take over their everyday lives continue to separate them from others. Secondly, historical understandings of mental illness in our society have mostly been neither kind nor accepting of those who are mentally ill. This sometimes means rejection by others and at other times results in others having lowered expectations for the participants.

In the extract below Michael talks about stigma and prejudice, attributing the attitudes of the present day to inherited understandings of the past. In addition Michael has ideas about how public education campaigns might work towards lessening stigma, but he is sceptical about whether "they" would take such action. Michael's words indicate that he believes both the problem and the solution to lie with the anonymous *they*.

> *I wish the stigma wasn't there against schizophrenia, like it is .... like people with heart problems don't have the same, people with cancer don't get the stigma that schizophrenic, people do, so, you know, its a real problem that, ... knowing that you can't open out of it,* [sic] *and I wish I could open out to more people, say that I've got schizophrenia, and they could be more sympathetic towards it, instead of .... passing it off as a big joke. That would be good, but that's the way it goes. You know, I think people of the old ages have got a lot to answer for, haven't they, you know, by .... people who are hearing voices, they used to burn them at the stake, and .... used to put them in chains, and do all sorts of things like that. ..//.. That's one reason why I don't work. It's because I find it very difficult to get back into the community. ..//.. Because of the stigma against schizophrenia. ..//.. You've got to divorce yourself from the community to a certain extent. Until the stigma is removed. ..//.. Or until a lot of its removed anyway. I'm sure, though, if they put it on the leading news item, on the TV news every night for about two weeks, that people would soon learn about it, and*

> *educate themselves about it. But they won't do that, though, that's only dreaming, but that's an example of. ..//.. Of what they should do, to remove the stigma.*
>
> (Michael 6, pp. 20-22)

While all participants endeavoured to fit into their social surroundings most of the time, there was a recognition by all of them that there were already some constraints on the possibilities of "fitting in" completely. Thus the combination of the experience of illness and their place amongst *the they* lead to many insightful comments from the participants regarding the nature of society and their place in it, and the need for them to pursue their own callings, to rely on themselves first and foremost. In a paradoxical way the difficulties of their lives could be seen to have freed the participants to be more themselves.

> In the authentic present's "moment of vision" (Augenblich) an individual can open up to the present realities of his life, since abandonment of the single minded pursuit of social acceptance allows him to adopt a free, nonmanipulative attitude toward his present situation.
>
> (Hoffman, 1993, pp. 207-208)

Both Michael and Chris were aware of the way that they altered what they said in light of the reception it might receive. Chris talked of the way he convinced his nurses and doctors that he understood his illness, likening his story to an anecdote he related about Isaac Newton's discovery of the colours of light. His story reflects the power of *the they* in producing conformist opinion. In reporting his tale he was amused by the analogy he had drawn and aware of the irony of the consequences for himself.

> *I pointed out the example of Newton working out the spectrum and he came up with six colours and they came along to him and said no six colours isn't the right number, we want seven colours.*
>
> (I remember you saying. And he invented .... violet?)
>
> *Indigo.* (Laughs). *And he convinced himself that indigo was another colour. He must have convinced himself. And*

> *everyone else was prepared to be convinced too. It's like in hospital they say to me "you're not going to get out of hospital unless you realise that you were sick at such and such a time." And so the next day I say yes I was sick and I believe it, I believe that I've reached self awareness. But I've done it because I had to. But it's not genuine understanding. I'm kidding myself and I'm kidding them. But that's all they'll get from me so they have to accept it.*
>
> (Chris 2, pp. 16-17)

It is not by accident that *they* appear in Chris's stories; here, too, is *the they* of Heidegger's analysis; the others to whom one cannot put a face or a name, *das Man*. Michael enjoys thinking deeply about many topics, as he told me on several occasions. He suggested that thinking about life is important in order to give it direction, and profound thinking may, in his view, be a corollary of schizophrenic illness. He suggested that actually *"some of the great philosophers in life have suffered from mental illness like schizophrenia"* which is why they have *"developed these different theories and statements, that they're suffering from schizophrenia and they've delved into them quite deeply"* (Michael 4, p. 7). As he explained, however, other people do not want to hear about many of the ideas that interest him and he therefore finds it wise *"to be a bit careful at times about what you say to people ..//.. and just talk about everyday things"* (Michael 6, p. 7). In terms of Heidegger's writing Michael's description here might be seen as a clear example of the way that to many people inauthentic speech or "idle talk" is more comfortable than authentic discourse.

> In order to avoid coming to grips with the unsettling deep truths about our being and world, we occupy ourselves with the kind of questioning of our being and world that can be satisfied by the superficial sense of things that (every) one has and by the kinds of irrelevant information that is the stuff of superficial conversation and gossip. And it is just such superficial conversation and gossip, "idle talk" for Heidegger, that makes up the inauthentic version of discourse. Having no deep understanding of things to communicate authentically to others, and afraid of being silent for fear of "hearing" the deeper truth about our being (the "call of conscience"), we engage in the kind of noisy chatter that never questions or gets below the

> anonymous public understanding of things and, hence, never really says anything.
>
> (Hall, 1993, pp. 138-9)

Jack's clarity about the nature of human existence and the social mores by which we live and are bound is captured in a lengthy section in one of his interviews, presented in abridged form here. That he understands the way in which our lives are constituted by the everyday choices we make is demonstrated in the last sentence of this extract, while the whole conveys his grasp of the situated nature of our freedom:

> *You're not totally free. We're all bound by convention. If you do certain things you'll suffer, they'll penalise you for it. If you don't pay your tax, there's trouble. If you don't give way at a give way sign, you're liable to get a fine. We're not free. We have a responsibility. We can't do what we like, we've got to consider the environment, animals, and that's coming more and more into it's own. ..//.. You got the environment people, the animal people, and the human rights people, which is good. ..//.. We're a product, we're a product or a victim of what the rest of the human race does. We're just an end product, of your parents, of the people you meet. Your systems control our lives, education, financial, all the rest. We're not individuals really, even in a democracy. You can go down to the middle of Wellington, on the soap box and start shouting about the wrongs of the world, well sooner or later someone's going to upset your applecart. ..//.. I suppose we're an end result of the lives that we've lived.*
>
> (Jack 5, pp. 14-16)

Understanding the situated nature of freedom and aware of their differences from others by virtue of their history and their illness experiences, all of the participants talked of their own personal values. Each worked actively toward maintaining these and strove for their hoped-for future. This is the challenge of authenticity.

> Dasein is authentically itself only to the extent that, *as* concernful Being-alongside and solicitous Being-with, it projects itself upon its ownmost potentiality-for-Being rather than upon the possibility of the they-self.
>
> (Heidegger, 1927/1962, p. 308)

The participants in this study had clear ideas in their own minds as to where they wished their lives to head. The things about which they cared, the things which made life meaningful and about which they took a stand were demonstrated in the way they conducted their everyday lives and in the content of the conversations we had during the time of data collection. A brief sketch of the stand of each of the participants follows.

### Taking a Stand: The Individual Participants

An introduction to the study participants was given in Chapter Three. Here a further sketch serves to describe the participants as individuals who are engaged in the world and taking a stand on the direction of their lives.

Roger was most keen to help other people in some way. He explained to me that he had had such a lot of help himself in the past that he felt the need to return some of this kindness. He had contemplated nursing as a career but been advised that it might be too difficult for him, so at the time of his meetings with me was studying a course designed to help him to care for people with mental illness. There were difficulties for him in completing his work in this regard because he often wrote about his own experiences and was marked down in his assignments as a result. Another avenue for helping others was through the church, and Roger moved frequently among churches, endeavouring to find the niche in which he could fulfil his potential as he saw it. As a church-goer Roger was acutely aware of what he believed to be a decline in moral standards in society at large. He was quick to assure me of his cleanliness as well as his high standard of morality. My impression was that Roger was lonely and shy, yet he continued his efforts to reach out to others.

Judith was the mother of a nine year old daughter, a responsibility which she took very seriously. Her efforts at finding an occupation in which she was able to succeed after her mental illness and a bad road accident were all directed toward her parenting and her contribution to her relationship with her partner. Having regrets about some aspects of her past life, particularly her involvement in drugs and some relationships she felt she had handled poorly, she was particularly determined that she should be the best possible guide and role model for her daughter. A strong sense of moral values pervaded Judith's conversations, as did her perseverance in her determination to do the best she could with the rest of her life.

Simon was the most highly educated of the participants and the only one to be engaged in fulltime employment. As he explained, his work and his children were the main focus in his life. He was in a position to be able to devote time and attention to some particular aspects of schizophrenia and felt that he brought a sense of integrity to his work, given his personal experiences with the illness. He, too, communicated a strong sense of moral values in his conversations with me.

Lucy was the youngest of the participants in the study. She had been unwell since early adolescence and at the time I met her was still in the process of breaking away from her parents and establishing her preferences in life. A talented painter, she held the Mexican artist Frida Kahlo as a hero. Lucy was lively, quick and interested in fashion, music, men and feminism, although there were several changes in the latest favourite topic on each occasion I visited her. Torn between wanting to be like everyone else, living up to the model her sisters provided for her and testing the waters for herself, Lucy exuded warmth toward people and an almost intoxicating enthusiasm for life in spite of all her past difficulties.

Michael was a husband and father, roles he took seriously yet enjoyed, and worked in a voluntary capacity for two groups related to the mentally ill. As the quotes from him in this chapter have shown, Michael enjoyed philosophising, although he apparently rarely shared his insights with others. He is a man who by his own admission *"puts on a brave face while inside there is a struggle."* The difficult position of the mentally ill in the community was something of which Michael was intently aware, and this issue had become a focus of his concern.

Adrian was the one participant least accepting of his diagnosis. His unusual position amongst the participants in this regard is referred to in relation to the notion of inauthenticity (p. 203). Since Adrian was not keen to talk about his illness I was not able to discover much about what had happened to him during the period in which he was admitted to hospital. At the present time Adrian conducts a regular routine in which he walks for several miles across town in search of work, making calls on businesses and employment agencies on a daily basis. As has been mentioned previously, he also holds a part time position which he operates from home. It could be suggested that Adrian's daily routine is a way of "losing himself" in busyness in an attempt to find a secure and comfortable place amongst others. His dismissal of his diagnosis of schizophrenia might also be likened to Heidegger's concept of *forgetting*.

> In the general strategy of an inauthentic Dasein, our sense of radical vulnerability and powerlessness becomes glossed over and made manageable by being projected onto the world. Whatever threats to our existence there may be, they are now viewed as threatening us from within the world. In conformity with this overall strategy, our entire future is seen as a pursuit of a secure acceptance by the world of the "they" (das Man). This understanding of the future entails a selective, highly utilitarian attitude towards one's past. Since successes and failures on the road of the inauthentic future are defined by the trends and pressures of the public world, an inauthentic Dasein's past will be disclosed through "forgetting." An individual will repress and relegate into oblivion such parts of his past as may prove detrimental to his search for success in the rapidly changing world of the "they" with all of this world's trends, fashions, and cliches.
>
> (Hoffman, 1993, p. 207)

Liz is a young woman who wishes to be seen as "normal." In our conversations she spoke of the way she sometimes felt that she had to *"fight for her own character,"* fearing that others, especially health professionals and members of the voluntary organisation for which she worked, saw her as unwell, as "schizophrenic" and as disabled. The latter word is one which is becoming more common in many publications about mental illness, and is also measured in percentage form in order that people may be judged eligible to receive an invalid benefit. Liz stood up staunchly for her right to associate with whomever she chose, to marry and have children even if they too might develop the illness, and to keep her past experiences to herself when she wished.

Nick is a very quiet and reserved young man who spoke of his desire to keep to himself. He owned a huge collection of video tapes of movies, rock concerts and tennis games and spent a considerable portion of each day on his own in his room. He expressed his desire to be independent and to avoid trouble, which he appeared to be doing well. While wishing for a quiet life, Nick also prays to God for *"things to turn out better"* for himself.

Jack is a friendly, sociable man who is also wary of people he does not know. His interest in science has been described earlier, and many of his future hopes for the world are dependent on new scientific discoveries. He is also a "small man's politician" in his own way, and he likes to champion the cause of the underdog. Jack admits to being very sensitive towards other people and animals and holds up as a hero an acquaintance who gave generously to charity over many years. Jack's belief in the importance of small gestures is summed up in his advice that *"you can always do something to help, even if it's just picking up a piece of glass off the street, we can all do something."*

Chris is a complex person, entertaining and yet serious. He possesses a strong will to succeed and expressed a belief that competition in society is a good thing since it makes people try hard. He has persevered to achieve many of his own goals, such as a position in much sought after housing and admission to the interview for a course he was keen to undertake. He has written several "autobiographical novels" based on his experiences and has submitted them for publication, though without success to date. Chris is intently aware of the finitude of life, to the extent that he contemplates suicide on a daily basis and has done for a considerable time. As he explained it, these thoughts take the form of a summing up of the day just past and an anticipation of the immediate future. He believes that he will end his life when he has achieved his goals and there is therefore nothing to look forward to.

> Authentic self-focussing is said to require such traits as resoluteness, steadiness, courage, and, above all, clear-sightedness about one's life as a finite, thrown projection. It calls for integrity and a lucid openness about what is relevant to one's actions. The authentic stance toward life makes us face up to the fact that to the extent we are building our own lives in all we do, we are "answerable" for the choices we make.
>
> (Guignon, 1993, p. 232)

The participants in this study demonstrated just such courage and determination in the stand they each took on their own life. Their individuality as people overrode the commonalities of their experience with schizophrenic illness and its treatment. In acknowledging and integrating their past experiences into their present life they display an acceptance of their fate and the confidence to take a stand on life in whatever way will best enable them to live up to their own potentiality-for-Being.

## REVIEW AND SUMMARY

Heidegger's notion of *care* is central to the discussion in this and the previous chapter. In Heidegger's view care is fundamental to our existence. It is *care* which makes human life meaningful, denoting as it does the way things matter to us, our involvement in the world and the sense we give to existence. It is in our being careful *(besorgt)* that our Being-in-the-world is made significant. In our everyday actions *care* is demonstrated by what we are concerned for and concerned with, and by our solicitude toward others.

In the previous chapter *care* was discussed in relation to the way the study participants understand their situation and the manner in which they comport themselves toward their world. In this chapter the discussion has been extended to include the participants' taking a stand on their life. In this way their actions, choices and moral stances are related to their future. It is also through their actions and choices that the participants most clearly demonstrate their individuality.

Because of the realisation of their difference from others and because of the life changing nature of their illness experiences, almost all the study participants have made a deliberate choice in taking a stand on their lives. The stand which each takes on his or her own life is quite an individual matter, reflecting the values and priorities held by each person. This stand is related to Heidegger's ideas of authenticity and inauthenticity which were also discussed in this chapter.

A further aspect to this discussion has been the identification and exploration of the nature and usefulness of the study participants' hopes and dreams. Hopes and dreams have been shown to be important in their comforting and motivating capacity, whether or not they appear to an outsider to be realistic or far fetched. Hopes and dreams are shown to be tied to both the past and the future, to be dependent on recognition and acceptance of past difficulties, and to be significantly tied to the stand that participants take on their lives.

The powerful nature of the schizophrenic experience and their standing outside of some of the expected ways of Being, whether consciously or not, have thrown the participants back on their resources and engendered in them a realisation that they need to be them-selves in the world. It is in Being them-selves that the individuality of the participants stands out over and above their common experience.

In the following chapter the findings presented in this and the previous three chapters will be summarised and integrated. In addressing the implications of the study for nursing practice, the discussion of *care* which began in the data chapters, is extended to include care as it is, or might be, incorporated in nursing actions and attitudes.

# CHAPTER EIGHT

# DISCUSSION

## Introduction

The purpose of this chapter is to summarise and integrate the findings of the study and to lead from discussion of the experience of schizophrenia to the implications of the study for nursing practice and education. The latter discussion will involve an extension of Heidegger's concept of care as it related to Being-with others. In the following section the implications of the study for nursing practice and education will be related both to the data and to Heidegger's concept of Fürsorge, or solicitude. The study will be shown to raise questions about some of the theoretical positions which, for many years, have informed nursing in the psychiatric setting. It will be suggested that modifications to traditional attitudes toward the mentally ill would result in nurse-client relationships which are more satisfying for both parties and hold the promise of improved client outcomes.

## Being-in-the-World with Schizophrenia

As the data presented in Chapters Four to Seven have shown, to live with a schizophrenic illness means to experience effects on one's whole Being-in-the-world. Although living independent lives in the community, and by clinical and their own standards "well," each of the study participants dealt on a daily basis with numerous effects of their treatment, the need for vigilance regarding their state of health, the legacy of their past episodes of illness, and with the knowledge of prejudicial community attitudes toward the mentally ill. The stories were not of "unrelenting suffering" which Gomez and Gomez (1991) describe as associated with schizophrenic illness, yet it was very clear that people who have this illness, if they are to remain well, must make a daily effort to do so. Schizophrenia has effects, directly or indirectly, on every facet of sufferers' lives. While holding on to hopes for a cure, the study participants' reality was of living with a chronic illness, with the fear of a future relapse and with residual symptoms even when the acute illness was in abeyance.

In the data chapters the experience of living with schizophrenia was related to Martin Heidegger's phenomenological writing, especially that in Part One of "Being and Time." In Chapter Four, the Being-in-the-world of the participants was described. Particular attention was paid to the way in which participants first realised that they were unwell and the way that, as a result of this realisation, they came to reconceptualise their own Being-in-the-world. The chapter also described some aspects of the experience of acute illness such as hallucinating, and the effects of both illness and treatment on the participants' lives. Such effects include the impact of medication on the body, the difficulty many participants found in controlling their thoughts, the altered relationships participants felt to the world, and the disturbing metaphysical effect of their being brought face to face with the relationship of mind and body.

A further aspect of Being-in-the-world is Being-with others. In Chapter Five discussion focused on the way the study participants found themselves alongside others, both in a personal and immediate sense, and as part of a society which is often less than understanding of their problems. All participants in the study found some of their relationships with others difficult. Not only did they have to contend with prejudice, of which they were often painfully aware, but often there was fear of other people or accounts of being uncomfortable in their company. Some of the fear or discomfort felt by participants was related to social attitudes. In other instances it was related to paranoid ideas, reticence, or the ongoing physical or metaphysical effects of the illness.

In spite of their discomfort, because participants recognised that it was important to stay engaged with others in the world, they worked hard at maintaining relationships they found helpful and sustaining, and actively sought relationships with others who were able to understand their experiences and difficulties. Illness and continuing treatment meant that there were times when the participants depended on others for help, either during an acute episode or on a continuing basis, or both. Health professionals were important in this regard and, as will be discussed in more detail later in this chapter, most participants had suggestions for improvements in these relationships. They reported valuing relationships where they felt understood, but worried about or avoided those in which they felt misunderstood or were treated unkindly.

All participants in the study worked hard at maintaining their health. In Chapter Six discussion centred on the ways in which participants acted carefully, conscious of the things they must do, and what must be avoided, to maintain their wellbeing. Two major themes were identified. In living circumspectly, the participants attended watchfully, cautiously and prudently to the details of their everyday lives. Such care included maintaining a routine and avoiding stress; taking prescribed medication and avoiding street drugs; monitoring thoughts, and managing finances. In addition they were conscious of their illness, recalling the past when they had been acutely unwell, yet letting this memory go in order to carry on with life, defining themselves as more than their illness. This recalling the past and letting it go was essential in order that participants were able to monitor their actions, aware of possible deteriorations in their health. They consistently balanced this awareness with a desire to move forward in their lives and to live as normally as possible. As will be discussed later in this chapter, other people, including family members and health professionals, were reported to have difficulty in letting go of their view of the person as "a patient" and consequently tended to worry about actions the participants felt did not warrant such concern.

The realisation that their illness and treatment - their thrownness as who they are in-the-world - was something they could not change yet which was often not well understood by others, led participants to rely on themselves, to work actively towards Being-themselves in the world. This aspect of attending to their own values and deliberately choosing to depend on themselves was elaborated in the final data chapter, Chapter Seven. This chapter emphasised the individuality of the participants and focused on the forward looking nature of their lives; their hopes and dreams and their thoughtful and moral stance - the stand they are taking on their individual lives - as reflected in their everyday actions and choices.

## The Relevance of the Phenomenological Approach

The narrative contained in the four data chapters illustrates the profound effect of schizophrenia on people's lives, even when they are living independently in the community and are well maintained on medication. As such, I believe it will serve a useful purpose in nursing education, where the use of people's stories has the potential to help students understand what an illness experience is like. For several years nurse educators have introduced fictional and autobiographical literature into their curricula as a means of introducing students to ideas from the humanities (eg. Peterson & Booth, 1988; Peden & Staten, 1994). Qualitative research findings may also be used to teach students about the experience of illness in a way which leaves them more equipped to understand such experiences when they meet patients in similar situations in clinical settings (Morse & Johnson, 1991).

A focus on scientific and technological knowledge in the health and human-caring sciences has been "at the expense of attention to values, ethics and the inner complexity of patients' subjective experiences" (Taylor & Watson, 1989, p. 3). Those who write of curriculum change incorporating phenomenological and narrative approaches in nursing education (eg. Baker & Diekelmann, 1994; Bevis & Watson, 1989; Diekelmann, 1990; 1992; 1993) suggest that when caring and interpretive approaches are foundational there is the potential for transformation of the profession and the of health care system. Darbyshire (1993, p. 508) describes this transformation as leading to the emergence of nursing as "a force dedicated not simply to servicing and staffing a sickness and cure system but to transforming this into a true caring-healing environment where the concerns of humanity and community can once again flourish."

In the present study, by using Heidegger's philosophical writing for the analysis of the lived experience of schizophrenia the author has been able to synthesise ideas from the humanities and research into the illness experience. It is a strength of the research that the implications go beyond the illness experience and speak to relationships between nurses and clients, suggesting what makes these interactions more, or less, helpful to clients. That the study was undertaken from a phenomenological viewpoint is important in this respect. As a new product, the phenomenological account goes further than simply restating the reported experience of the individual participants. This is the power of the method.

> Phenomenology does not simply iterate what is already given and understood in lived experience in the way that it is given and understood. It seeks a transcending theoretical understanding that goes beyond lived experience to situate it, to judge it, to comprehend it, endowing lived experience with new

> meaning. Without this transcendence, phenomenology would be superfluous.
>
> (Burch, 1989, p. 192)

Burch (1989) suggests that the practical benefit of phenomenology is to be found in what the method "does to us." A phenomenological study is useful not simply because of what it "finds," or the written account which is presented as a result, but because it aims to change our understanding. In a study aimed at increasing nursing knowledge, phenomenological research has a practical effect when changed understandings are carried forward into practice settings. The changes which the study suggests could be carried into practice are the focus of the discussion in this chapter.

It is fundamental to a phenomenological analysis that we (researcher, clinician, reader) endeavour to put aside our prior theoretical understandings, returning instead to the things themselves in order to gain a renewed understanding of something which we thought we already knew. In this study returning to the things themselves meant asking people with schizophrenia what this illness experience is like and how their illness has affected their life. As I explained in Chapter Three (p. 84) even posing the question meant stepping outside of many of the theoretical understandings which are held about mental illness in our society.

As an illness which has been recognised for over 100 years, schizophrenia is one which has lead its sufferers to be regarded as different from the rest of society. In the first two chapters of the thesis the cultural and historical legacy of our understanding of schizophrenia was outlined and discussed. Particular attention was paid to the writings of Porter (1987a, 1987b) and Gilman (1988) in this regard. Their claim that we have inherited a deep disposition to see madness as Other is echoed in research such as that by Barham (1992) who suggests that we have lost sight of the *person* who suffers from mental illness. Discussion in Chapter One pointed to the need to attend to the experience of people with the illness in order to improve the care they receive.

At the outset of this study I was challenged by several people who believed that it would not be possible to find an answer to the question "What it is like to be-in-the-world with schizophrenia?" Those who challenged the study suggested that I might not find enough participants to meet the criteria of wellness and independent living, that I would not obtain comprehensible answers or that participants would not be able to relate their experiences accurately or with insight. None of these problems in fact arose. I experienced few problems in locating potential study participants and found all who took part both willing and able to communicate their experiences in a way which I could understand. Several were thoughtful to the point of eloquence.

The present study demonstrates that it is practicable to attend to the subjective experiences of people who suffer from schizophrenia, to understand more about their needs and their desires and to do so from a position of fellow human being, without the need of a guiding theory from which to interpret what they are saying or what their words "really mean." Such a stance is quite different from the commonly described needs or problem based approach (eg. Peplau, 1989; Reynolds & Cormack, 1990) and requires a degree and kind of involvement on the part of the nurse which, as was discussed in Chapter Two, is only recently being recognised in the psychiatric nursing literature.

Attention to the experience of those with a schizophrenic illness surfaced expressions of severe emotional and spiritual pain, distress, and the relivings of past traumatic events. But the participants also related amusing stories, told of their desire for ordinariness and a "normal" life, and expressed hopes and dreams for the future. The overwhelming impression with which I was left was of their immense courage in the face of suffering and difficulty and of the humanity we all share. While the individual circumstances of the participants varied widely, as I came to know them better as data collection proceeded, I became less and less aware of our differences and more of the human predicament in which we all find ourselves. Krim (1964, p. 63) wrote "one day the prisoners of this definition [insanity] will walk beside us sharing only the insane plight of mortality itself, which makes quiet madmen of us all."

For me one of the most striking aspects of this study was the demonstrated courage, determination and individuality of the participants. While their lives were in no respect easy and in many respects extremely difficult, they were each actively engaged in the world in their own way, looking toward the future and maintaining a personal moral stance in their manner of Being-in-the-world. All had had to face distressing experiences as a result of illness, needed to live carefully in the present and dealt with the ongoing side effects of medication and the stigma associated with mental illness. Yet they persevered.

Participants in the study saw themselves as defined not by their illness, but by their individual personalities and attributes and the aspects of their lives which made their existence meaningful. While several harboured dreams of greatness (as do many of the general population) most also expressed a simultaneous desire for ordinariness, as did the participants in the study by Lorencz (1991, discussed in Chapter Two, p. 68). A wish to be seen as ordinary, unremarkable, to fit in, while commonly experienced, is one not often expressed in our society. It is a poignant desire which serves to highlight how conscious the study participants were of both their difference from and their similarity to other members of their society. Given the bizarre nature of many of their experiences while acutely ill, it is a powerful reminder that people are more than an illness.

Because of their experiences with illness and treatment and the problems encountered in their daily lives, the study participants recognised over time that in some ways they were not like most other people. In addition, historical understandings in our society have resulted in attitudes in the wider community which are often neither kind nor accepting toward those with mental illness. As a result participants realised that there were constraints on the possibilities of their fitting in completely to their social surroundings. It consequently became necessary for them to rely on themselves, to be true to what they believed, to act on their own values and to shape their lives in the way that felt right for them. Mulhall (1990, p. 116) explains that Heidegger "conceives of Dasein as necessarily understanding itself in terms of its possibilities, which are grasped in their essences as possibilities and which permit Dasein to say to itself 'Become what you are'."

In a paradoxical way the difficulties they had faced in their lives could be seen to have freed the study participants to be more fully themselves and less concerned with what others expected them to be. Whether consciously or not, each strove toward his or her own potentiality-for-Being, all shaping their lives through their choices in everyday matters, as indeed Heidegger suggested we all do.

While struggling with difficulties particular to their way of Being-in-the-world, their thrownness as people with a schizophrenic illness, the study participants nevertheless continue to live lives which are concerned with the matters that are important to everyone. They are first and foremost individuals with individual problems, worries, talents, plans and desires. The fact that they live with the problems of a schizophrenic illness is secondary, although the illness and its sequelae pose such powerful effects on everyday life that they cannot, and should not, be ignored.

On the one hand, people who suffer a schizophrenic illness share their common humanity with everyone else. On the other, even when well they face difficulties related to their illness and its treatment which set them apart from other people. It is in the face of this predicament that Heidegger's concept of solicitude, as concern for others, offers a promising way for nursing to proceed.

## Care, Solicitude and Nursing

As has been emphasised at various points throughout this thesis, the concept of **care** is central to Heidegger's analysis of Being-in-the-world. Heidegger's conceptualisation of care is a broader one than that in common everyday usage. It encompasses concern for the things that matter to us and for other people. Heidegger actually postulates that "Dasein's Being is care" (p. 329). His use of the word "care" is a well developed one, although it is difficult to discuss care unambiguously in relation to nursing since the discipline contains multiple definitions of care and of caring, to the extent that fruitful use of the concept has reached something of an impasse.

Some authors suggest that caring is definitive of nursing, while others hold that delineation of the profession is not possible along these lines. Nor is the term used with uniformity by the numerous authors who identify its importance in nursing. Among the authors who claim that caring is the essence or core of nursing are Leininger (1981), Watson (1985), and Swanson (1993). Leininger's definition of caring as involving assistive, supportive and enabling behaviours towards others puts her work in the category of caring as therapeutic intervention. Watson's assertion that caring is the moral ideal of nursing, and her identification of ten carative factors by which caring is enacted in practice indicate that her theoretical position involves several dimensions of caring.

Swanson's model of caring includes the component of therapeutic intervention, in "doing for" and "enabling." More recently Wolf, Giardino, Osborne & Ambrose (1994) identified a different set of behaviours which constitute caring. They propose five dimensions of nurse caring behaviours: respectful deference to others; assurance of human presence; positive connectedness; professional knowledge and skill; and attentiveness to the other's experience. These can be compared to the five perspectives on caring identified by Morse, Solberg, Neander, Bottorff and Johnson (1990) in their analysis of thirty five definitions in the nursing literature. They contend that views of caring in the nursing literature can be classified into those which define caring as a human trait, as an affect, as a moral imperative or ideal, as an interpersonal relationship or as a therapeutic intervention.

It is beyond the scope of this thesis to examine the uses of the term "care" in any depth. What is important is that the continuing debate regarding its centrality in the discipline is recognised. Some critics (eg. Carson, 1994) suggest that while caring is essential to nursing, as a human trait it is accessible to many other groups and thus cannot be used to define nursing. Others, including Morse et al (1990) contend that the elusiveness of the concepts of care and caring are an impediment to the development of understanding (and research) in this area, and that care is too vague a concept to fully capture the essence of nursing. Still other authors, such as Benner and Wrubel (1989) and Dreyfus (1994), who draw on Heidegger's work, remain confident in their interpretation of the term, based as it is on an extensive philosophical argument. It is this interpretation of care which is carried forward in the discussion in this chapter.

Benner and Wrubel (1989) follow Heidegger's position that caring is a way of Being-in-the-world, and suggest that "nursing is viewed as a caring practice whose science is guided by the moral art and ethics of care and responsibility" (p. xi). Dreyfus, in his Preface to Benner's (1994) work, identifies actions and attitudes which spring from a caring stance. "Caring, in the context of illness, consists in keeping open the possibilities that can be saved in the world of the sick person, while aiding the person in letting go of possibilities that are no longer realistic" (p. ix).

The multiple, overlapping views of caring in the nursing literature have contributed to the disciplinary confusion which surrounds the use of the term. That the sentiment and the actions represented by the concept are important to the discipline is not in doubt. Rather the impasse might be seen to have resulted from our difficulties in articulating much of nursing practice.

One of the problems with the concept of caring is a semantic one. As Dreyfus (1994) points out, perhaps because cure, and the medical discourse which accompanies it, has been a predominant concern, we do not have adequate words in our language to describe the complexity of the skills involved in *caring* for others.

> Caring is what one might call an existential skill. ...It shows the power of a tradition based on the theory of disease that the existential skills of caring have no traditional name that does honour to their importance and uniqueness, and we seem to have no appropriate word for them in our vocabulary.
>
> (Dreyfus, 1994, pp. ix - x)

Dreyfus goes on to suggest that neither caring nor curing (medicine) can be determined, in their application, by theoretical prescription. While the attitude of caring may be advocated, its practice is particularistic and individual. The "existential skill" is engaged in a particular situation. The knowledgeable practitioner involved in a one-to-one relationship with a particular client is "able to take on the perspective of the patient and make his or her peace with the situation and its suffering in order to be touched by the situation of a fellow human being." He goes on to emphasise that "they must have the tact to enable that person to face, surmount or weather his or her illness. Only by combining technological and existential skills can we approach healing the embodied person" (Dreyfus, 1994, p. x). The position described by Dreyfus is precisely the one identified as relating to nursing the person with schizophrenia, who is on the one hand a fellow human being, and on the other troubled by specific difficulties inherent in his or her illness.

In Heidegger's analysis **care** (Sorge) encompasses concern for entities or things in the world, and for other people. In "Being and Time" the term used to refer to care for others is Fürsorge, translated as solicitude.[1] This form of care often involves a "factical social arrangement" (a social mandate) (Heidegger, 1927/1972, p. 158) as does nursing.

Solicitude may take one of two forms. At one extreme solicitude "leaps in" for the other, intervening, deputising, or standing in for him. Heidegger suggests that this kind of solicitude is common when our concern is for things in the world around us. Thus a solicitous person might help with a practical task, or take it over completely for the other person. As Benner and Wrubel (1989) point out, this form of care is necessary in nursing when patients are acutely ill or dependent.

In the other mode, solicitude is the kind of care which "leaps ahead" of the other in his potentiality-for-Being. As such this kind of solicitude is concerned with aiding the other's growth as a person, with helping the other to become what he is able to be. Benner and Wrubel (1989, p. 49) suggest that this form of care in nursing is a form of "advocacy and facilitation" and is the goal in all nursing relationships.

> This kind of solicitude pertains essentially to authentic care - that is, to the existence of the Other, not to a *"what"* with which he is concerned; it helps the Other to become transparent to himself in his care and become *free for* it.
>
> (Heidegger, 1927/1962, pp. 158-159)

In Heidegger's analysis, the recognition of our Being-with others in the world is central to solicitude. Being-in-the-world encompasses Being-with others. It is not simply that other people exist in the way that objects exist, but rather that, as Dasein, each of us is concerned with the things that matter to us. In the fact of our existing we are faced with a world similar to that of other Dasein.

---

[1] The translators' note in "Being and Time" (1927/1962, p. 157) registers the lack of an adequate English word for Fürsorge, whose etymological connection to Sorge (care) and concern (Besorgen) is lost in the word "solicitude." Fürsorge is explained as being the kind of care referred to in "taking care of the children," "prenatal care," or the care administered by welfare agencies.

In the previous four chapters the nature of the "circumspectively concernful Being-in-the-world" of the study participants has been described and a picture built up of the experience of Being-in-the-world with schizophrenia. Experiences of illness such as those described by the study participants are not shared generally amongst people in any community, but Heidegger's analysis points out that the fact of being concerned about the things that matter to us is a condition of human existence. In sharing this existential state we are all alike.

The understanding of another person which enables the kind of solicitude demonstrated in care which "leaps ahead" might be referred to as empathy. Heidegger (1927/1962) maintains that empathy is possible only on the basis of a genuine Being-with. Only when we are able to understand ourselves and grasp the essential nature of our Being-with others is empathy possible. Heidegger explains that empathy is then not the first route to understanding another, but is itself dependent on Being-with in a way which contrasts with the indifference and unsociability common to everyday, dominant modes of Being-with.

> To summarise Heidegger's point: when analysing the issue of understanding the "psychical life of Others," we should not take phenomena such as empathy to be the first ontological bridge between two self-contained subjects, but rather recognise that empathy (or indeed misunderstanding) becomes possible only on the basis of Being-with. We share the world with other people, not merely with organisms whose human status is in doubt.
>
> (Mulhall, 1990, p. 116)

Caring is thus dependent on an appreciation of the existential nature of human Being-in-the-world, and the transparency of our Being-with each other as "an irreducible relationship of Being" (Heidegger, 1927/1962, p. 162). In this form, caring is tied to our Being-with another in his or her world. "To care for another person, I must be able to understand him and his world as if I were inside it. I must be able to see, as it were, with his eyes what his world is like to him and how he sees himself" (Mayeroff, 1971, pp. 41-42). He continues, "in the broad sense, 'being with' characterises the process of caring itself: in caring for another person we can be said to be basically with him in his world, in contrast to simply knowing about him from outside" (p. 43). In order to be with someone in his or her world, it is necessary to understand as much as is possible of that world, as he or she lives it.

Mayeroff (1971, p. 42) speaks of going into a person's world "in order to sense from 'inside' what life is like for him, what he is striving to be, and what he requires to grow." This is a possibility offered by the phenomenological approach. As this study demonstrates, it is possible to shed light on the experience of others even when that experience is foreign to the one enquiring (researcher or nurse) provided the questioning is approached in an appropriate way.

Care, as solicitude, "is guided by *considerateness* and *forbearance*" (Heidegger, 1927/1962, p. 159). In the context of nursing, a caring, solicitous attitude requires recognition of the effect of illness on the whole of a person's life. Such an attitude means that we listen to the person's experience, neither dismissing it in favour of a diagnosis, nor normalising it to the point where it is invisible and seen as unimportant. In the mental health field there is a danger that, in rejecting the biomedical model of illness and acknowledging the perils of labelling people through the application of a psychiatric diagnosis, we may, however inadvertently, fail to recognise that those who have suffered a severe mental illness continue to be faced with challenges in their everyday life, even when the illness is in remission. Barham and Hayward (1991, p. 5) warn that while there is a form of medical reductionism which takes little account of the effects of illness on the person, "there is also an opposing form of normalising discourse in which difference comes to be glossed over or denied, as though a benign regard or the force of good intentions could prise away the stubborn reality of chronic mental illness."

A solicitous attitude means suspending theoretical interpretations and attending to what it is that the person (client) is experiencing. This is an approach which runs counter to some beliefs commonly held in the mental health field. There is, for example, a long-standing belief, derived from Freudian theory, that the perceptions of the mentally ill are to be regarded with suspicion. Kaplan (1964, p. vii) sums up this position:

> The whole of the Freudian tradition is based on the conception that the patient's experience is a self-deception and that his reality is hidden from him. In fact, the personality itself is

> organised around a core of defensive structures which insulate him from experiencing the truth about himself....What the patient experiences is tied to illness and irreality, to perverseness and distortion. The process of psychotherapy consists in large part of the patient's abandoning his false subjective perspectives for the therapist's objective ones. But the essence of this conception is that the psychiatrist understands what is going on, and the patient does not.

While Kaplan (1964) writes of the relationship between patient and psychiatrist, it is important to recognise that nursing practice in psychiatric settings has also derived much of its traditional base from psychoanalytic theory, and that nurses have often also been wary of accepting patients' reports at face value. This position is reinforced by a legacy of conceptual frameworks which emphasise the need for, or simply assume, distance between patients/clients and nurses. In these models we are advised to bring the client into our reality (denying that of the individual) as if the former were the only one. While this action may be necessary in acute stages of illness as a way of reducing fear and disorientation, it is not appropriate in ongoing stages in which the person is managing well in the community. In fact it is argued in this thesis that such a stance is both unnecessary and unhelpful under such circumstances.

The manner in which some nurses in the psychiatric setting distrust patients' motives and maintain distance between themselves and the patient was described by Morse (1991, p. 466):

> One strategy that some psychiatric nurses used for maintaining distance between themselves and the patient was not trusting the patient, by always being vigilant, and by suspecting the patient of having an ulterior motive when they engage in behaviours designed to connect with the nurse. This is ironic for this lack of trust from the caregiver could conceivably increase the patient's pathology and paranoia. Maintaining a therapeutic relationship in psychiatry appears to be one of the most difficult aspects of caring for patients in this specialty.

There are times in the interactions between nurse and client where an attitude of suspicion and distrust may be both necessary and therapeutic, as, for instance, when a client is believed to be acutely suicidal or likely to harm others. Skilled nursing requires recognition of the signs of impending illness, yet people also need closeness, communicated concern, validation of their feelings and their abilities and to be responded to in their humanness rather than in a doubtful, distrusting way. In this circumstance solicitude may be exhibited, temporarily, in the form of "leaping in" and taking control. This is a situation full of paradoxes and difficulties, and calls for expertness in nursing. A fine line then, is to be drawn between distance and closeness, between professional objectivity and a recognition of shared existential situatedness. Expert nursing practice in this context is complex, particular, knowledgeable and intuitive. Perhaps what is most central to the approach based on care (solicitude) is that the model "does not limit itself to a prescribed interpretation of human difficulties" (Montgomery and Webster, 1993, p. 293). Not only does the caring approach not limit itself to prior or prescribed theoretical interpretations, but such interpretations are antithetical to the caring approach.

The experience of the study participants, discussed in the previous four chapters, highlights several ways in which a caring solicitous approach on the part of nurses or other health professionals was both desired by the participants and would be effective in helping them deal with the specific problems brought about by their illness. As the participants in this study have described, it is no easy thing to come to terms with having a mental illness. In the very early stages of illness participants did not doubt their perceptions but rather behaved as if their world was meaningful, carrying out the actions which followed their understandings, however bizarre these actions might appear to others. Graphic descriptions of this stage of illness are given by Liz (p. 103) in her explanation of not doubting herself, Chris (p. 106) who rationalised his thoughts as being related to political ideas or fashion, and Lucy (pp. 108-109) who feared that other people would hear what her voices were saying, or would wonder why she had put rats in her hair.

In seeking to understand what was happening to them, participants looked outside themselves *to the world* for the source of puzzlement which signalled the beginning of a psychotic illness. Their first experience of illness was one of living in a world which had somehow changed or become threatening. Thus people hid from others who were believed to be out to harm them, scrutinised the actions of others, or tried to explain to others the dangers they feared in previously innocuous situations. In experiencing the world as somehow different, they became unsure of themselves in their worldly relationships and connections. At this moment the "web of relationships and possible actions" described by Moss (1978, p. 83) became tangled and unpredictable. Careful, solicitous nursing in this situation requires that the nurse attend to the patient's fear and listen to and accept his or her experiences, while attempting to understand this experience as far as possible.

Over a period of time the participants came to accept that it was not the world which had changed but rather that their relationship with the things in the world was distorted because of an illness. In part this realisation came about as a result of treatment: it was only when they were able to experience themselves in a restored relationship to the world that they could understand that they had in fact been ill. Such an understanding requires accepting a diagnosis (even if only tentatively) and reconceptualising one's whole way of Being-in-the-world. Participants had to **in-corporate**, literally to **take into themselves**, the idea of their suffering from an illness from which they might never fully recover, which is stigmatised in our society, and which involves experiences which can be profoundly frightening. When Liz (p. 110) stated that she did not know that "normal" people do not hear voices, she suggests that education regarding her illness might have helped her come to terms with it earlier.

During periods of acute illness, participants experienced episodes of terrifying visions, voices and tactile sensations, overwhelming urges to commit suicide, or fears that others were intent on humiliating them or endeavouring to kill them. Some, such as Liz, experienced rapturous feelings of power and connection to the supernatural which were not understood by others. Others, like Lucy (p. 111) and Jack (pp. 113-114), had the experience of being unable to comprehend what people were saying to them. Neither family members nor health professionals were believed to be exempt from ulterior motives at this time and most participants at this stage felt that everyone was to be treated with suspicion. Such experiences are dramatically more intense than "thoughts," instead being lived by the whole person. As was emphasised in Chapter Four (pp. 107-108) one *hears* voices, *sees* things, *feels* restless, anxious or afraid. In part the difficulty participants had in explaining some of these experiences to their satisfaction reflects their bodily nature - they are sensations to be communicated not just thoughts to be related. In addition, people who have not had such experiences do not have a similar frame of reference with which to compare and thus understand them.

It is tempting for nurses and other health professionals to try to find some means of locating ground from which to understand an experience such as that of hallucinating. One suggestion is that hallucinations experienced in a psychotic illness may be likened to those induced by drugs, or in trance-like religious experiences. The descriptions of hallucinations given by participants in this study support the contention of Oxman et al (1988), referred to in Chapter Two (p. 63), that this is an inadequate analogy. Unsatisfying as it may be, perhaps it is necessary simply to acknowledge that most of us have not had and can not share the experiences of those who have had a psychotic illness. It therefore becomes more important to listen attentively to others' experiences and to avoid closing off our listening on the assumption that we can, or might, understand through an analogous experience.

Similarly, problems arise out of the use of formal models and the language with which health care professionals describe the common features of a particular illness. Benner (1984, p. 241) warns that dependence on formal models and language can result in mystification:

> Speech and thought become sloganised and formalised to such an extent that very narrow and unquestioned discourse takes place, obscuring the complexity of the actual situation for the actors....There is also a danger that people *think* they know what they mean when in fact they don't, or that the meanings become so general as to be meaningless.

In this study several participants described experiences which were in no way adequately explained by the professional language which purports to categorise them. If nurses are satisfied with the professional discourse they will fail to appreciate the complex problem which faces the client. In turn they will fail to appreciate the possibilities which present themselves as solutions to the problem, or, if no solution can be found, the degree of distress and disability which the problem causes the individual.

Examples are to be found in the way in which, whether due to residual effects of the illness or to medication, several participants reported difficulty in engaging themselves in some activities. These were real problems of the embodied self which are poorly reflected in the psychiatric terminology used to categorise them, such as the terms "avolition" or "lack of motivation." Jack (p. 117) reported being so occupied with his own thoughts that he was unable to carry out activities he enjoyed. Persistent thoughts occupied much of his and the mental life of several other study participants. Many spoke of having to deal with several thoughts simultaneously. This is not only distracting and confusing, it also can be extremely tiring. Some participants were unable to read more than a few sentences at a time as they found it impossible to keep to their train of thought, while conversations with others could be difficult for the same reason. Thoughts sometimes interfered directly with other activities - this was especially so when the persistent thoughts were anxious or worried ones, or when unhappy thoughts continued remorselessly, as did Chris' night time suicidal ideas.

Tiredness and sleepiness were common side effects of medication, but the origin of another problem, that of action and achievement was not clear. Several people reported a need to *force themselves* to do things, including everyday activities like getting out of bed, and were at pains to describe both the intensity of this feeling that the body was difficult to propel into the world and their desire to counter the feeling if they could. Michael (p. 119) describes this situation very powerfully. It was not through a lack of intention that he failed to achieve things, but rather because of a felt lack of bodily energy with which to follow through on desired actions. To dismiss this experience as a "lack of motivation" is both to underestimate its powerfully disturbing effect on the person and to attribute a lack of will which is erroneous. Such a categorisation also appears, through naming, to explain something which for the study participants was inexplicable and close to intolerable, and for which there was no help available. In this situation acknowledgement of his difficulty rather than its dismissal through the language of symptomatology would have offered some consolation, even when no practical help could be given.

Almost without exception, Being-in-the-world with a schizophrenic illness means facing particular difficulties and challenges in encounters with others. Here nursing skill is required in the fostering of satisfying human relationships within the capacity of the individual client and in concert with his or her own goals. In Chapter Five several study participants described their difficulties in relationships with others, and the remedies they have found for particularly difficult situations. Mindful care incorporates the plans and desires of individuals into a broader plan of professional action. Roger's description of his goals for attendance at church and his desire to sit at the front and stay for an entire service (p. 144) is an excellent example of the kind of goal which nurses could help people work towards.

Although frequently uncomfortable in the company of others the study participants all recognised their needs for friendship and human contact. They thus worked actively toward staying engaged with others in-the-world, endeavouring to conquer their discomfort in social situations and to find others who would and could understand their experiences. Several participants, including Jack, Michael, Liz, Chris, Nick and Adrian had social networks comprised largely of others who had suffered a mental illness. On the one hand, friendships had often been forged while they were in psychiatric care either in hospital or the community (or had resulted from contact at a support group or through shared housing). On the other, as friends they had had similar experiences from which to understand the other's past and present concerns. As Chris (p. 155) explained, he and his fellow ex-psychiatric patient friends had no secrets from each other. In a society where mental illness is feared, it is not surprising that people found it comforting to have friends from whom there was no need to hide important aspects of their lives. On the other hand, most participants had, or hoped for, friendships with "normal" people (a term they themselves used) - those who have never had a psychiatric illness.

For some people a caring nurse is considered a "normal" friend, one who is able to help with practical problem-solving, give advice and warm regard yet who asks for little in return except that the person does his or her best to help him or herself. Certainly several study participants talked of particular nurses, with whom they had good relationships, in this light. Nurses also find satisfaction in relationships such as these, and some authors (eg. Benner, 1984) go so far to suggest that warm relationships with clients offer nurses some protection against burnout.

The description Liz (pp. 152-153) gave of the relationship she and her fiance had with a nurse in a community house identifies her desire for a personal rather than a "professional" relationship. She explains that the form of caring exhibited by the nurse in this context felt remote and distant and that she was seen not as a person but as a patient. Later in Chapter Five (p. 156) Liz talks of the way in which her relationship with her fiance was discouraged and disapproved by health professionals, not because of their personal compatibility but because of their shared diagnosis.

In the context of nursing in the community, a solicitous attitude means nurses are challenged to let go of "the patient" and see the person instead. Unfortunately, as Liz explained, this is not always realised. Sometimes, asking her nurse about a problem or telling her of some difficulty resulted in Liz's being seen as vulnerable and close to relapse, even when she believed she was managing well. The lack of trust she felt in this nurse as a consequence of the incident she described (pp. 187-188) has resulted in her communicating less with the nurse. Opportunities for reinforcement of her strengths and for learning about how best to manage her illness were lost as a result. Lucy (p. 187) has faced similar problems in relations with her parents, whom she believes scrutinise her behaviour, becoming alarmed and worried if she exhibits any intense emotion. There are implications here for the role of the nurse in helping family members also let go of their view of the person as "sick."

It is not just the immediate reward of personal warmth which was sought in relationships with nurses and other health professionals. As Simon (pp. 146-147) explained, when illness occurs in adolescence people may miss out on learning important social skills. He believes he would have benefited from learning about friendship from nurses and others. The relationship the participants desired was one in which there was mutual trust. Jack had such a relationship with some nurses. As he explained, (p. 178) he felt that the night nurse he telephoned when he was becoming unwell understood him and his problems and could be depended on. As a result he was able to avoid hospitalisation and was reinforced in his ability to care for his own health. Jack's reference to the "nurses" who work at the local mental health centre, compared with the "guards" who nursed at the hospital he found himself in forty years ago is testimony to the care with which the former treat him, and to the comfort and security he experiences as a result.

In order to live successfully with their illness and to prevent relapse, each of the participants described means by which they watched themselves carefully for warning signs and were cautious and prudent in their everyday activities, maintaining routines and avoiding stress wherever possible. Those things which were stressful varied considerably between participants; here their individuality was most important, but all had developed a way of living circumspectly in which they took care of themselves and paid attention to their activities and choices on a day to day basis. Everyday life was in many ways more organised and required more effort than is true for most without such an illness.

The narrative provided by the participants in this study suggested that if nursing is to be founded on an understanding of the person's world as he or she sees it then it has to incorporate knowledge of the strategies the client uses in order to maintain health, and of the things which are of concern to him or her. Nurses would then be able to adapt to client routines rather than have clients adapt to the nurse's. They would then understand why spontaneous changes of plan are difficult, and identify possibilities in terms of social activities within the limits of the client's comfort. Careful assessment of this kind might also identify problems, for example with regard to medication, such as were implicit in Judith's complaints of being overly sleepy (p. 119) and Lucy's descriptions of the huge doses of caffeine with which she aimed to counteract the effect of her medication (p. 120).

The health care professional who listens carefully to the experience of the client will find opportunities for teaching, for learning about the illness and the way it is managed and for supporting help-seeking behaviour as reflecting a recognition of early warning signs rather than seeing it as a sign of dependence. Focusing on wellness rather than illness may be a useful way of helping people with schizophrenia to learn about their own health, and to maintain continuity with their support networks. These are important considerations in an illness where relapses are so devastating (Hamera, Pallikkathayil, Bauer & Burton, 1994).

While New Zealand society today is arguably more accepting of those with mental illness than it was 50 or 100 years ago, prejudice against the mentally ill is still evident in many areas. A fear of violence by those with a psychiatric history is common, and throughout the period of this study media reports of, and perhaps encouraging, such community fears were common. The move toward community housing, as large psychiatric hospitals are closed, has been praised in some areas, but widely criticised also. People with mental illness live in an atmosphere of prejudice and misunderstanding much of the time. Many participants in the study suggested that widespread educational programmes aimed at informing the public about the nature of schizophrenia are desperately needed. There is potential for nurses to be involved in the design and delivery of programmes which would serve toward this purpose.

Several participants in this study have had to withstand unkind, sometimes hostile, treatment from people in the community at large. Some have experienced cruel or unthinking comments made to them personally. At other times the participants, as members of a stigmatised group, have had deal with their pain, anger and frustration as they have read, watched and listened to uninformed and inaccurate comments made in the media or by the public at large. There is a real need for support, comfort and reassurance in these situations, and nurses taking the advocacy role may well be in a position to help people speak out against injustice.

As individuals with very different talents, values, aims and ambitions, in this aspect of their lives the study participants held few aspirations in common. Yet all could be seen to be looking forward to their future and striving to fulfil their own hopes and dreams. Heidegger (1927/1962) emphasises that hope is not simply a forward looking expectation but is also intensely bound to the past. It is only through acknowledging our own past hurts and disappointments and accepting our thrownness, the way we are in-the-world, that we are able to move forward toward the things we hope for ourselves. Simon (p. 140) and Liz (p. 184) both clearly explained the importance of their illness and past experience in their lives - schizophrenia is part of who they are. Health professionals who know the history of a person's illness are thus in a privileged position, yet as was discussed earlier, they must learn, as the sufferers do, to move forward and let go of a view of the person as "patient."

The discussion in Chapter Seven centred on the forward looking, thoughtful and moral stance participants are taking on their lives. Among the hopes held by these people were those for a cure for their illness, for a satisfying family life, a home of their own, or achievement or fame of some kind. Judged against the expectations health care professionals might hold as to likely future possibilities for the individuals concerned, some of these aspirations would be deemed highly unrealistic. Yet all people harbour dreams which provide hope and comfort. To dismiss the hopes and dreams of people with mental illness as grandiose or delusional, as some theoretical or diagnostic guidelines might suggest, is to deny the imaginative, creative and meaningful nature of such thoughts. Hopes and dreams serve the function of directing attention toward the future, one which may be seen in a positive light, however difficult the individual's past may have been. Nursing based on solicitude is fundamentally concerned with helping people look toward future goals, appreciating current achievements and focusing on the positive aspects of the person's life, which involve much more than their illness.

Some aspects of the illness experience extend into the spiritual or metaphysical realm. The effect of medication on their thoughts lead, for several participants, to a deep realisation of the relation between mind and body. Since a drug could so dramatically overturn apparently fixed beliefs, participants came to experience the connection between mind and body in a fundamental and disturbing way. The understanding that "one's mind is a mechanism" (Simon, p. 127) is a life-changing one, a realisation with which most people never come face to face in this way. Participants were confronted by questions about the nature of existence which for most of us belong to the philosophical realm, but which stemmed, for them, directly from their experiences - from the way in which they found themselves thrown into the world.

It is possible that a client might wish to talk about this realisation, this existential crisis, with his or her nurse. The challenge posed to the nurse in such a situation is one which demonstrates clearly how no theoretical answer could prescribe a response. Engaged caring in this circumstance can only be individualised, contextual, and intuitively directed, depending as it does on the relationship between the two people, client and nurse.

In suggesting that a caring stance is important in nursing those with mental illness I do not in any way mean to devalue the degree of skill which expert practice entails in the variety of settings in which psychiatric nursing is carried out. I do, however, suggest that each nurse needs to evaluate the models and theoretical frameworks from which he or she practices. Some of them may have outworn their usefulness. We cannot simply impose caring attitudes on top of incompatible theoretical perspectives and hope it will work.

Care of the kind advocated in this thesis requires knowledgeable skilled practitioners. In the current climate of cost-cutting, deinstitutionalisation and the rhetoric of "normalising" (addressed on p. 226) we are facing a "progressive de-skilling of staff involved in the care of people with serious mental disorders" (Lennane, 1993, p. 7). Given the complexity of the illness, the care of people with schizophrenia ought not to be handed over to an entirely untrained, nonprofessional group of "carers." Care which is based on understanding the illness and the person's experience requires knowledge from a range of disciplines. As Mayeroff (1971, p. 13) cautions

> We sometimes speak as if caring did not require knowledge, as if caring for someone, for example, were simply a matter of good intentions or warm regard. But in order to care I must understand the other's needs and I must be able to respond properly to them, and clearly good intentions do not guarantee this. To care for someone I must know many things. I must know, for example, who the other is, what his powers and limitations are, what his needs are, and what is conducive to his growth; I must know how to respond to his needs, and what my own powers and limitations are.

The kind of caring to which Mayeroff refers is central to nursing. It depends on understanding the other and on acting with the considerateness and forbearance of which solicitude is comprised. In turn, solicitude is dependent on an appreciation of the shared existential nature of all human Being-in-the-world. It requires the suspension of prior theoretical explanations and attention to the experience of illness in a way which enables the nurse, in as far as is possible, not only to see the world as the person who is the patient does, but also to assist that person to become what he or she is capable of becoming.

## REVIEW AND SUMMARY

This chapter has served to summarise the findings of the study as they were presented in Chapters Four to Seven and to identify the implications of the study for nursing practice and education. It was argued that the phenomenological approach taken in the study has surfaced findings which challenge some of the theoretical positions regarding nurse-client relationships which have been held in mental health settings for many years. Discussion has thus extended beyond the understanding of the lived experience of schizophrenia offered by the study to the implications of the study for nursing practice.

The Heideggerian concept of care, which was discussed in relation to the data in Chapters Six and Seven, was extended in the present chapter, in relation to Being-with others and concern for others. Since care is a word which is used in multiple ways in the nursing literature, a brief overview of its uses was presented, the discussion then focusing on Heidegger's concept of solicitude as care for others. Solicitude was identified as a promising concept for guiding nursing practice with those suffering from schizophrenia.

In the final chapter, which follows, the thesis as a whole will be reviewed, its boundaries identified and directions for future research suggested.

# CHAPTER NINE

# CONCLUSION

This last chapter of the thesis provides a brief review the study as a whole, identifying its boundaries and suggesting fruitful directions for future research in the area of schizophrenia and psychiatric/mental health nursing practice. The chapter, and the thesis, end with the claim that this research has contributed to nursing knowledge through making accessible understandings which have previously been thought inaccessible, and through relating this understanding to its implications for nursing practice and mental health care.

The research aimed to answer the question "What is it like to live with schizophrenia?" As researcher I sought to discover how people who are well and living in the community conduct their lives in the shadow of possible further episodes of acute illness, what residual difficulties they face and the methods they employ to deal with such problems. Until recently little research has been conducted in this area since people who suffer from schizophrenia have been believed unable to communicate their experience in a way which is meaningful to those who have not shared it. The experience of this mysterious illness has been argued to be simply incomprehensible (Jaspers, 1913/1963; Sass, 1992a).

The phenomenological method of inquiry was chosen for the study because it was seen to be the most suitable means by which to come to a greater understanding of human experience, and to provide access to experience in such a way that it can be made explicit. The study was conducted from the premise that understanding the experience of illness as it is lived is a vital part of the knowledge from which expert nursing derives. From the many possibilities, Heidegger's hermeneutic approach was chosen as the research method and philosophy.

As the study progressed the good fit between this form of interpretive phenomenology and the research question became increasingly apparent and ideas and themes from Heidegger's early writing proved a useful and fitting frame for the organisation and discussion of the data. The use of Heidegger's phenomenological writing in the organisation of the data and reflection on the words and experiences of the study participants emphasised the humanness of the participants. Paradoxically, the phenomenological perspective, as well as uncovering commonalities, has also proved a way in which greater insight can be gained into the experience of the person with schizophrenia and "the profound way his form of life differs from the normal" (Sass, 1992b, p. 117).

The data provide a compelling narrative which illustrates that to live with a schizophrenic illness is to experience powerful effects on one's whole Being-in-the-world. Each of the study participants dealt on a daily basis with the effects of their treatment, the legacy of their past experience of illness, the constant need to monitor their state of health, and the knowledge that their illness is one which evokes prejudice and invites stigma. Within the account of the participants' experiences are indications of the way in which community care, and nursing in particular, can be shaped so as to be genuinely supportive. There are important implications for relationships between nurses and clients.

Life with schizophrenia has been shown to comprise, on the one hand, an existence which is fraught with numerous difficulties, both real and potential, and on the other, a life which is concerned with the things which concern all people in this society. In recognising the shared existential predicament into which we are all thrown, I have endeavoured to reflect both the similarity of the participants' experience with that of all of us, and the differences which pertain to the particular thrownness of the participants, the way in which schizophrenia has impacted on their Being-in-the-world. The fit between Heidegger's ideas and the stories told by the study participants is a powerful feature of the study. In essence, they told me not only what it is like to live with an illness as devastating as schizophrenia, but what it is like to be a human being in the world. It is from this basis that the discussion was extended from the central focus of the research, the lived experience of schizophrenia, to its greater aim, which is to use the understanding so generated to inform nursing practice.

Discussion centred on the implications of the study for nursing practice drew on Heidegger's concept of solicitude (Fürsorge), or care for others. It was argued that solicitude, as a particular form of care, provides a basis for nursing action which rests on understanding the experience of the client. The writings of Benner and Wrubel (1989) and Dreyfus (1994), who also draw heavily on Heidegger's work, were of particular relevance in this regard. It was acknowledged that the contemporary debate about the place of care in nursing has reached something of an impasse. While some authors claim that caring is the essence or core of nursing, others argue that the concept is poorly defined and that preoccupation with caring blinds the discipline to more profitable avenues of enquiry. This argument notwithstanding, an understanding of care based on Heidegger's notion of solicitude is argued to be a very promising one in situations such as those described in this study.

In reviewing the participants' stories in light of their implications for nursing, challenges they pose to some commonly held theoretical beliefs in the mental health field were exposed, and the argument made that relationships of a more equal nature, in which nurses use their multiple skills in an effort to understand the experience of their clients and to work toward the clients' own goals, hold promise for more satisfying outcomes for both parties. This position is in line with the move toward more equal relationships between clients and nurses identified earlier as apparent in the nursing literature.

While there is as yet no cure for schizophrenia, it is clearly possible for people who live with the illness to lead satisfying, productive lives, as did many of the participants in this study, in spite of the limitations caused by their illness and its treatment. However, for some, although life is constructed and enacted "as normal" (Robinson, 1993), it is often difficult and lonely, while contact with health professionals has not always been pleasant or seen as helpful. The prospect of skilled nursing input and warm human relationships fostering more satisfying outcomes for people with schizophrenia was a central focus of the discussion in the previous chapter.

## The Limits of the Study

As with all phenomenological research the account of this study as presented in the thesis is only one of several possibilities for the same story. As Denzin and Lincoln (1994, p. 11) point out, each researcher brings a "gendered, multiculturally situated" perspective to a qualitative research project. To attempt to sum up my own background in this way, in a few words, would be to trivialise its importance, while also presuming that it would be possible to capture all the elements which have coloured my conduct in every phase of this research. Instead I have endeavoured to remain conscious of my own part in the research process, and have documented my reactions where I believe it is important that the reader be aware of them. The intuitive process is an essential part of phenomenological research, requiring "the researcher to be hyperattentive to his or her own feelings, values and beliefs, and to their influence on the research process. It also demands that the researcher be able to move back and forth between understanding self and understanding the participant" (Paterson, 1994, p. 309).

The written account of a phenomenological study involves a series of transformations of experience (Reinharz, 1983). First the participants in the study put their experience into words, thus making it accessible to the researcher. The researcher grasps the essence of the experience and translates his or her understanding into a written account, thus making the participants' experience available in a textual form to the reader. The final transformation of experience occurs in the understanding gained by the reader of the text. It is the task of the phenomenological researcher to bring to speech that which has been uncovered in the process of the study (van Manen, 1990).

This thesis, then, is my account of my encounters over a four year period with ten people with a schizophrenic illness, with the stories contained in the data collected, with the emerging themes through which the data have been organised and with the written work which is the end product of this particular project. In it I have aimed to capture and present for the reader "evocative, true-to-life, and meaningful portraits, stories and landscapes of human experience" which Sandelowski (1993, p. 1) describes as constituting the best test of rigour in qualitative research. I have also endeavoured to leave a "decision trail" such as Sandelowski (1986) recommends, in order that readers may audit the work.

Participation in this study required that the person be known to the Schizophrenia Fellowship and possess good verbal skills. Those whose illness was unstable were precluded from taking part. As a result the participants are probably not fully representative of those with schizophrenia in the community. While representativeness is not a requirement in phenomenological research, it is important to recognise that there are many people who are not known to Schizophrenia Fellowship, are less stable in their illness, less well housed and perhaps receive less in the way of community support than do the participants in this study. Baseline figures for those in the New Zealand community do not exist for comparison. It remains for further research to seek out these people before it can be presumed that conclusions from the present study have meaning for the wider community of schizophrenia sufferers.

Similarly it is acknowledged that the study involved participants from only one cultural group and included more men than women. Neither of these factors was intentional, nor does it imply that schizophrenia is culture specific or that its effects are more significant for men than women. Certainly more research is needed to clarify the influence of culture, ethnicity and gender on the experience of schizophrenia and other forms of mental illness. The wider society needs to understand these matters if pressure is to be brought to bear on policy makers to provide appropriate and culturally sensitive health services.

Constraints of time and resources for this research, some because it was conducted as a PhD study, have meant that participant numbers were small. On the other hand the range of living circumstances, occupation, age and experience among the participants is wider than I expected and I believe adds to the credibility of the findings. In the writing of the thesis I experienced some tension between being absolutely honest and wanting to shield participants from being identifiable and from possible harm. New Zealand is a small country, the numbers of participants in the study limited, and both nurses and community workers often well known to each other. My solution has been to withhold specific details about some participants and their stories which would almost certainly have lead to their identification in some quarters. Although these details, which related to such things as appearance, occupation, living conditions and family structure were important to my analysis, I believe their omission from the final account does not detract from the accuracy of the study.

In the selection of participants for the study no attempt was made to control for the type of schizophrenia with which participants had been diagnosed. It was considered satisfactory for the purposes of the study that the participant identified as having such an illness and was currently taking some kind of neuroleptic medication. As is common in those with severe mental illness, some participants had actually received several diagnoses, for example the line between schizophrenia and schizo-affective disorder was unclear for three participants who had held each diagnosis at some time. In a phenomenological study one assumes that an experience is what a person describes it as being. Self identification as one with schizophrenia was an adequate criterion and medical confirmation was not sought. However, in participant selection two further criteria; the person's being known to Schizophrenia Fellowship and judged by officers there to have the illness, and their being prescribed antipsychotic medication, were also applied.

## Suggestions for Future Research

This study represents a step forward in research which uncovers and makes explicit what it is like to live with a schizophrenic illness. Given the lack of research into this aspect of illness, demonstrated in the opening chapters of this thesis, there is a real need for further research into the subjective experience of schizophrenia and other mental illnesses. As has been identified, one such need is for research which examines the experience of people other than Pakeha[1] New Zealanders. Where Maori experience is concerned the prevailing view is at present that Maori research is best defined and conducted by Maori. Certainly the cultural appropriateness of health care services would be enhanced by the kind of understanding to which such research could give rise. Another need is for research which considers the experience of those who are known to be managing poorly in the community. Baseline demographic figures about those who suffer serious mental illness in the New Zealand community are not currently available; if such information were at hand other research questions which have important implications for service delivery and for policy would undoubtedly become apparent.

There is a need also for research which examines the influence of gender on the experience of mental illness. Do men and women experience mental illness similarly, or are there particular problems related to being a male or female and suffering such an illness? How are social gender roles affected by severe mental illness?

This research focused on one mental illness in particular. Similar research which examines the experience of those in other diagnostic categories would be useful in informing the practice of nurses and other health care workers. How comparable, for instance, is the experience of those who suffer from bipolar illness, and what comparisons can be made between the experience of those with major, as opposed to less serious forms of mental illness? In addition, further work is needed to examine the nursing interventions and relational styles which clients and their families find most helpful and supportive. Such research might include evaluation of the nursing implications suggested in the present study.

---

[1] Non-Maori - New Zealand European. The term Palagi might also be used for this group of New Zealanders, distinguishing them from Pacific Islanders.

A further, important research focus would examine expert nursing practice with this and other client groups in the New Zealand setting. As yet, in this country, there has been little research aimed at identifying the expert skills embedded in clinical psychiatric nursing practice, either in acute settings or the community. Given the intricacies of the situations in which psychiatric nursing is required and the practical, embodied, contextual and intuitive skill of practitioners in this clinical specialty, there is a very real need for research into expert psychiatric nursing practice, as it is judged by peers, families and clients of the service.

In the previous chapter solicitude was identified as an attitude of care ideally suited to nursing relationships with mentally ill clients such as those in this study. Educational research which identifies how to teach attitudes of caring and solicitude, to nurses at pre- and post registration level is urgently needed. If clinical practice is to be based on such skills and attitudes students need to know how to live and practice these attitudes, not simply to know about them.

## CONCLUDING STATEMENT

This study arose from a belief that it was possible to understand more about what it is like to live with a schizophrenic illness, and that this understanding would serve a useful purpose in informing nursing practice. The evidence of this research confirms that this is indeed the case. The phenomenological method has proved a most suitable one by which to uncover many aspects of the experience of schizophrenia, in a way which refutes the apprehension, referred to at the beginning of the study (p. 2), that "the mad cannot explain and the sane cannot comprehend." Each of the participants in this study has had at least one episode of acute schizophrenia, and has therefore at some stage and by some criteria been "mad." Yet they were each able to relate at least part of their experience, sometimes with devastating eloquence. The evidence is contained in this thesis, in powerful descriptions of the effects of illness, both acute and residual, on every facet of their lives.

Further phenomenological research is needed to add to the knowledge gained here, but a useful start has been made. The next challenge is to see that the knowledge uncovered in this study is translated into understanding which is carried forward into practice and policy making. Both practitioners and educators have key roles to play here. For researchers there is an open invitation to extend understanding of the experience of nursing practice and education in relation to schizophrenia.

## Appendix I

# THE LIVED EXPERIENCE OF SCHIZOPHRENIA

## Information Sheet

My name is Jo Ann Walton. As part of my work toward a university nursing degree, I am undertaking a study to understand more about what it is like to live with the illness known as schizophrenia. Knowing more about schizophrenia from the sufferer's point of view will help nurses, doctors and other health professionals in the future to understand and plan care for people with this problem.

Participants in my study will be asked to talk with me on several occasions at times arranged as suitable to us both, and at an agreed place. I would like to tape record our conversations so that I can accurately record what we say. Parts of the tapes will later be transcribed. We will talk about everyday things and about what is going on in your life at that time.

If you agree to take part in the study, you have the right to several things:

(1) you may ask any questions about the study that occur to you during your participation, and I will do my best to answer them.

(2) you can choose not to answer any particular question, or decide that you do not want to talk to me at any time. You can request to have the tape recorder turned off if you wish. You also have the right to withdraw from the study at any time.

(3) the information you provide will be used only in my research. I will not use your name in my report and it will not be possible for you to be identified in any reports that are prepared from the study. I will keep the tapes of our conversations in a secure place, accessible only to me. The only people to listen to the tapes will be me, my study supervisors and a typist whom I may employ to help me.

(4) you have the right to a copy of our discussions, either on tape or as a written transcript, if you wish. When the study is written up in PhD form a copy will be held at the Massey University library and I will also lodge a copy with Schizophrenia Fellowship. A copy of any other report I write will also be left with the Fellowship, where you will have access to it.

If you have any further questions I can be contacted at the Nursing Studies Department, Massey University, telephone number (06) 3569099, extension 7471.

## Appendix II

# THE LIVED EXPERIENCE OF SCHIZOPHRENIA

## Consent Form

I have read the Information Sheet for this study and have had the details of the study explained to me. My questions about the study have been answered to my satisfaction, and I understand that I am free to withdraw from the study at any time, or to choose not to answer any questions I do not wish to. I agree to provide information to the researcher, Jo Ann Walton, on the understanding that it is to be used only in her research and that I will not be identified in any written reporrt of the study.

I agree to participate in this study under the conditions set out in the Information Sheet.

Signed:

| | |
|---|---|
| (Participant) | (Researcher) |

Date:

## Appendix III

## SPECIAL CONSENT FORM

I hereby give permission for Jo Ann Walton to use a copy of my work, as detailed below, in her research report or teaching.

Signed:

Name:

# Appendix IV

## GLOSSARY

## DRUGS TAKEN BY STUDY PARTICIPANTS

### Names and Actions

| | |
|---|---|
| Betaloc | Metoprolol as the succinate. A beta-adrenoreceptor blocker used in hypertension, angina pectoris, and disturbances of cardiac rhythm. |
| Butyrophenones | A class of antipsychotic drug. Includes Serenace, Haldol and Droperidol. |
| Carbamazepine | Tegretol or Tegretol S.R. (slow release). Anticonvulsant and antimanic. |
| Chlorpromazine | Chlorpromazine hydrochloride. Largactil: an antipsychotic of the phenothiazine group. |
| Cogentin | Benztropine mesylate. Anticholinergic, antiparkinsonian. Used to counteract side effects of antipsychotic medication. |
| Flupenthixol | Flupenthixol decanoate in oily syrup. Depixol. Long acting injection; antipsychotic of thioxanthene group. |
| Frusemide | Lasix. Diuretic. |
| Haloperidol | Serenace. Antipsychotic - butyrophenone. |
| Haldol | Haloperidol as the decanoate. Long acting injection. |

| | |
|---|---|
| Lithium carbonate | Lithicarb. Antipsychotic used in manic phases of manic depressive psychosis. |
| Methotrimiprazine | Methotrimiprazine hydrochloride. Nozanin. Antipsychotic - phenothiazine. |
| Modecate | Fluphenazine decanoate in sesame oil. Antipsychotic - phenothiazine. |
| Perphenazine | Trilafon. Antipsychotic - phenothiazine. |
| Pimozide | Orap. Antipsychotic. Diphenylbutylpiperidine. |
| Phenothiazines | Class of antipsychotic agents, including three sub-groups: aliphatic compounds, piperidine compounds and piperazine compunds. The group includes the drugs Largactil, Melleril, Modecate, and Nozanin. |
| Prozac | Fluoxetine hydrochloride. Antidepressant - serotonin uptake inhibitor. |
| Prazosin | Prazosin hydrochloride. Minipress, Hyprosin, Pratsiol. alpha1-adrenoceptor blocker. |
| Procyclidine | Procyclidine hydrochloride. Kemadrin. Anticholinergic, antiparkinsonian. Used to alleviate side effects of antipsychotic agents. |
| Thioridazine | Thioridazine hydrochloride. Melleril. Antipsychotic, anxiolytic - phenothiazine. |
| Thiothixene | Navane. Antipsychotic - thioxanthene. |
| Trifluoperazine | Trifluoperazine dihydrochloride. Stelazine. Anxiolytic, antiemetic, antipsychotic - phenothiazine. |

# References used in compiling glossary

American Medical Association. (1995). *Drug evaluations annual.*

McKenry, L. M., & Salerno, E. (1995). *Mosby's pharmacology in nursing*. St Louis: Mosby.

*New Ethicals.* (1993). 30(2) Auckland: Adis International.

# REFERENCES

Abbott, F. K. (1992). *Daily lives of persons with schizophrenia living in the community*. Unpublished doctoral thesis, University of California, San Francisco.

Abbott, M. (1992, June). *Aetiology of mental health in New Zealand.* Paper presented at the Symposium on social science perspectives on epidemiological transitions and health in New Zealand. Massey University, Palmerston North, NZ:

Aiken, L. H. (1987). Unmet needs of the chronically mentally ill: Will nursing respond? *Image: Journal of Nursing Scholarship, 19(3),* 121-125.

Aldiss, B. W. (1990). Introduction: Kafka's sister. In B. W. Aldiss (Ed.), *My Madness: The selected writings of Anna Kavan* (pp. vi-xiv). London: Pan Books.

American Psychiatric Association (1987). *Diagnostic and statistical manual of mental disorders* (3rd ed., Rev.). Washington, DC: Author.

Andreasen, N. C. (1984). *The broken brain.* New York: Harper and Row.

Andreasen, N. C. (1987). The diagnosis of schizophrenia. *Schizophrenia Bulletin, 13(1),* 9-22.

Anonymous (1989). First person account: A delicate balance. *Schizophrenia Bulletin, 15(2),* 345-346.

Anthony, W. A., Cohen, M. R., & Cohen, B. F. (1983). Philosophy, treatment process, and principles of the psychiatric rehabilitation approach. *New Directions in Mental Health, 17,* 67-79.

Anthony, W. A., & Liberman, R. P. (1986). The practice of psychiatric rehabilitation: Historical, conceptual, and research base. *Schizophrenia Bulletin, 12 (4),* 542-559.

As in dreams. (1975). In J. Wing (Ed.), *Schizophrenia from within* (pp. 45-47). Surbiton, Surrey: National Schizophrenia Fellowship.

Bachrach, L. L. (1986). Dimensions of disability in the chronic mentally ill. *Hospital and Community Psychiatry, 37(10),* 981-982.

Bachrach, L. L. (1988). Defining chronic mental illness: A concept paper. *Hospital and Community Psychiatry, 39(4),* 383-388.

Baker, C., & Diekelmann, N. (1994). Connecting conversations of caring: Recalling the narrative to clinical practice. *Nursing Outlook, 42,* 65-70.

Banonis, B. C. (1989). The lived experience of recovering from addiction: a phenomenological study. *Nursing Science Quarterly, 2(1),* 37-43.

Barham, P. (1992). *Closing the asylum.* London: Penguin Books.

Barham, P., & Hayward, R. (1991). *From the mental patient to the person.* London: Routledge.

Barker, P. (1989). Reflections on the philosophy of caring in mental health. *International Journal of Nursing Studies, 26(2),* 131-141.

Beck, C. T. (1992). The lived experience of postpartum depression: a phenomenological study. *Nursing Research, 41(3),* 166-170.

Beebe, L. H. (1990). Reframe your outlook on recidivism. *Journal of Psychosocial Nursing, 28(9),* 31-33.

Benner, P. (1984). *From novice to expert. Excellence and power in clinical nursing practice.* Menlo Park, Ca: Addison-Wesley.

Benner, P. (1985). Quality of life: a phenomenological perspective on explanation, prediction, and understanding in nursing science. *Advances in Nursing Science, 8(1),* 1-14.

Benner, P., & Wrubel, J. (1989). *The primacy of caring.* Menlo Park, Ca: Addison-Wesley.

Bentall, R. P. (1990). Concluding remarks. Schizophrenia - a suitable case for treatment? In R. P. Bentall (Ed.), *Reconstructing schizophrenia* (pp. 283-296). London: Routledge.

Bevis, O. E., & Watson, J. (Eds.). (1989). *Toward a caring curriculum: A new pedagogy for nursing*. New York: National League for Nursing.

Binswanger, L. (1963). *Being-in-the-world: Selected papers of Ludwig Binswanger* (J. Needleman, Trans.). New York: Basic Books.

Birchwood, M. J., Hallett, S. E., & Preston, M. C. (1988). *Schizophrenia: An integrated approach to research and treatment.* London: Longman.

Birchwood, M., Macmillan, F., & Smith, J. (1992). Early intervention. In M. Birchwood & N. Tarrier (Eds.), *Innovations in the psychological management of schizophrenia* (pp. 115-145). Chichester: John Wiley & Sons.

Bleuler, E. (1911/1950). *Dementia Praecox or The group of schizophrenias* (J. Zinkin, Trans.). New York: International Universities Press.

Bleuler, M. (1991). The concept of schizophrenia in Europe during the last one hundred years. In W. F. J. Flack, D. M. Miller, & M. Wiener (Eds.), *What is schizophrenia?* (pp. 1-15). New York: Springer-Verlag.

Bloom, F. E. (1993). Advancing a neurodevelopmental origin for schizophrenia. *Archives of General Psychiatry, 50*, 224-227.

Boddy, J. M. (1992). *An ethnography of caring and control in an acute psychiatric unit.* Unpublished doctoral thesis, Massey University, Palmerston North, NZ.

Bollnow, O. F. (1974). The objectivity of the humanities and the essence of truth. *Philosophy Today (Spring)*, 3-18.

Boyle, M. (1990). *Schizophrenia - a scientific delusion?* London: Routledge.

Breier, A., Buchanan, R. W., Kirkpatrick, B., Davis, O. R., Irish, D., Summerfelt, A., & Carpenter, W. T. (1994). Effects of clozapine on positive and negative symptoms in outpatients with schizophrenia. *American Journal of Psychiatry, 151(1),* 20-26.

Bryson, K. K., Naqvi, A., Callahan, P., & Fontenot, D. (1990). Brief admission program. An alliance of inpatient care and outpatient case management. *Journal of Psychosocial Nursing, 28(12),* 19-23.

Burch, R. (1989). On phenomenology and its practices. *Phenomenology + Pedagogy, 7,* 187-217.

Burnard, P. (1989). Mental Health. Fads and Fashions. *Nursing Times, 85(8),* 69-71.

Bynum, W. F., Porter, R., & Shepherd, M. (Eds.). (1985). *The anatomy of madness*. London: Tavistock.

Carson, V. (1994). Caring: The rediscovery of our nursing roots. *Perspectives in Psychiatric Care, 30(2),* 4-6.

Chafetz, L. (1990). Withdrawal from the homeless mentally ill. *Community Mental Health Journal, 26(5),* 449-461.

Cleghorn, J. M., Franco, S., Szechtman, B., Kaplan, R. D., Szechtman, H., Brown, G. M., Nahmias, C., & Garnett, E. S. (1992). Toward a brain map of auditory hallucinations. *American Journal of Psychiatry, 149,* 1062-1069.

Cleghorn, J. M., & Lee, B. L. (1991). *Understanding and treating mental illness: The strengths and limits of modern psychiatry.* New York: Hogrefe & Huber.

Clozapine Study Group, (1993). The safety and efficacy of clozapine in severe treatment-resistant schizophrenic patients in the UK. *British Journal of Psychiatry, 163,* 150-154.

Cohen, C. I. (1993). The biomedicalization of psychiatry: a critical overview. *Community Mental Health Hournal, 29(6)*, 509-521.

Connelly, C. E., & Dilonardo, J. D. (1993). Self-care issues with chronically ill psychotic clients. *Perspectives in Psychiatric Care, 29(4)*, 31-35.

Corcoran , R., & Frith, C. D. (1993). Neuropsychology and neurophysiology in schizophrenia. *Current Opinion in Psychiatry, 6*, 74-79.

Darbyshire, P. (1993). Preserving nurse caring in a destitute time (Editorial). *Journal of Advanced Nursing, 18*, 507-508.

Davidson, L. (1992). Developing an empirical-phenomenological approach to schizophrenia research. *Journal of Phenomenological Psychology, 23(1)*, 3-15.

Denzin, N. K., & Lincoln, Y. S. (1994). Introduction. Entering the field of qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 1-17), Thousand Oaks: Sage.

Deveson, A. (1992). Foreword. In L. Folkard (Ed.), *The rock pillow*. (pp. 9-12) Fremantle, Western Australia: Fremantle Arts Centre Press.

Diekelmann, N. L. (1990). Nursing education: Caring, dialogue and practice. *Journal of Nursing Education, 29*, 300-305.

Diekelmann, N. L. (1992). Learning-as-testing: A Heideggerian hermeneutical analysis of the lived experiences of students and teachers in nursing. *Advances in Nursing Science, 14(3)*, 72-83.

Diekelmann, N. L. (1993). Behavioural pedagogy: A Heideggerian hermeneutical analysis of the lived experiences of students and teachers in baccalaureate nursing education. *Journal of Nursing Education, 32*, 245-250.

Disley, B. (1989). Stigma. *Mental Health News, (December)*, 8-12.

Dostal, R. J. (1993). Time and phenomenology in Husserl and Heidegger. In C. Guignon (Ed.), *The Cambridge companion to Heidegger* (pp. 141-169). Cambridge: Cambridge University Press.

Dreyfus, H. L. (1994). Preface. In P. Benner (Ed.), *Interpretive phenomenology: Embodiment, caring, and ethics in health and illness* (pp. vii-xi). Thousand Oaks, CA: Sage

Durie, M. (1994). Maori psychiatric admissions: Patterns and policies. In J. Spicer, A. Trlin, & J. A. Walton (Eds.), *Social dimensions of health and disease: New Zealand pespectives.* (pp. 323-335). Palmerston North, NZ: The Dunmore Press.

Dzurec, L. C. (1990). How do they see themselves? Self-perception and functioning for people with chronic schizophrenia. *Journal of Psychosocial Nursing, 28(8)*, 10-14.

Ellard, J. (1992). New white elephants for old sacred cows: Some notes on diagnosis. *Australian and New Zealand Journal of Psychiatry, 26*, 546-549.

Estroff, S. E. (1981). *Making it crazy.* Berkeley, Ca: University of California Press.

Falloon, I. R. H. (1985). *Family management of schizophrenia.* Baltimore: Johns Hopkins Press.

Fetter, M. S., & Lowery, B. J. (1992). Psychiatric rehospitalization of the severely mentally ill: Patient and staff perspectives. *Nursing Research, 41(5)*, 301-305.

Flack, W. F. J., Miller, D. R., & Wiener, M. (Eds.). (1991). *What is schizophrenia?* New York: Springer-Verlag.

Folkard, L. (1992). *The rock pillow.* Fremantle, Western Australia: Fremantle Arts Centre Press.

Foucault, M. (1961/1965). *Madness and civilization* (R. Howard, Trans.). New York: Random House.

Frame, J. (1961). *Faces in the water.* Christchurch: Pegasus Press.

Frede, D. (1993). The question of being: Heidegger's project. In C. Guignon (Ed.), *The Cambridge companion to Heidegger* (pp. 42-69). Cambridge: Cambridge University Press.

Freedman, B., & Chapman, L. J. (1973). Early subjective experience in schizophrenic episodes. *Journal of Abnormal Psychology, 82(1),* 46-54.

Gilman, S. L. (1988). *Disease and representation.* Ithaca, NY: Cornell University Press.

Godschalx, S. M. (1989). Experiencing life with a psychiatric disability. In J. T. Maurin (Ed.), *Chronic mental illness: coping strategies* (pp. 3-29). Thorofare, N.J.: Slack.

Goffman, E. (1961). *Asylums: Essays on the social situation of mental patients and other inmates.* Garden City: N.Y.: Doubleday Anchor.

Goldman, H. H., & Morrissey, J. P. (1985). The alchemy of mental health policy: Homelessness and the fourth cycle of reform. *American Journal of Public Health, 75 (7),* 727-731.

Gomez, G. E., & Gomez, E. A. (1991). Chronic schizophrenia: the major health problem of the century. *Perpectives in Psychiatric Care, 27(1),* 7-9.

Greenfeld, D., Struass, J. S., Bowers, M. B., & Mandelkern, M. (1989). Insight and interpretation of illness in recovery from psychosis. *Schizophrenia Bulletin, 15(2),* 245-252.

Guignon, C. B. (1984). Heidegger's "authenticity" revisited. *Review of Metaphysics, 38,* 321-339.

Guignon, C. B. (Ed.). (1993). *The Cambridge companion to Heidegger*. Cambridge: Cambridge University Press.

Gullickson, C. (1993). My death nearing its future: a Heideggerian hermeneutical analysis of the lived experience of persons with chronic illness. *Journal of Advanced Nursing, 18*, 1386-1392.

Haber, J., McMahon, A. L., Price-Hoskins, P., & Sideleau, B. F. (1992). *Comprehensive psychiatric nursing*. St Louis: Mosby Year Book.

Hall, H. (1993). Intentionality and world: Division I of Being and Time. In C. B. Guignon (Ed.), *The Cambridge companion to Heidegger* (pp. 122-140). Cambridge: Cambridge University Press.

Hamera, E. K., Pallikkathayil, L., Bauer, S., & Burton, M. R. (1994). Descriptions of wellness by individuals with schizophrenia. *Western Journal of Nursing Research, 16(3)*, 288-300.

Harding, C. M., Zubin, J., & Strauss, J. S. (1992). Chronicity in schizophrenia: Revisited. *British Journal of Psychiatry, 161 (suppl. 18)*, 27-37.

Hartmann, L. (1992). Presidential Address: Reflections on humane values and biopsychosocial integration. *American Journal of Psychiatry, 149(9)*, 1135-1147.

Hawthorne, D. (1993, November). *Effective practice with long term community clients: A grounded theory project*. Paper presented at the Australian College of Psychiatric Nurses Annual Conference, Sydney.

Haxell, M. (1992). The accommodation for mental health society (AHMS) North Shore (Inc). *Mental Health News (Autumn)*, 22-25.

Heidegger, M. (1927/1962). *Being and Time* (J. Macquarrie & E. Robinson, Trans.). Oxford: Basil Blackwell Ltd.

Heidegger, M. (1927/1977). Being and Time: Introduction. In D. F. Krell (Ed.), *Basic Writings* (pp. 41-89). San Francisco: Harper San Francisco.

Hicks, M. B. (1989). A community sojourn from the perspective of one who relapsed. *Issues in Mental Health Nursing, 10*, 137-147.

Hirsch, S. R., & Bristow, M. F. (1993). Psychological, family, ethnic and community factors affecting the course and treatment of schizophrenia. *Current Opinion in Psychiatry, 6*, 53-57.

Hoffman, A. L., & Bertus, P. A. (1992). Theory and practice: Bridging scientists' and practitioners' roles. *Archives of Psychiatric Nursing, 6(1)*, 2-9.

Hoffman, P. (1993). Death, time, history: Division II of Being and Time. In C. B. Guignon (Ed.), *The Cambridge companion to Heidegger* (pp. 195-214). Cambridge: Cambridge University Press.

Hogg, L., & Hall, J. (1992). Management of long-term impairments and challenging behaviour. In M. Birchwood & N. Tarrier (Eds.), *Innovations in the psychological management of schizophrenia* (pp. 171-203). Chichester: John Wiley & Sons.

Horgan, J. (1990). Overview: Schizophrenia. *Scientific American, (June)*, 16-17.

Hoy, D. C. (1993). Heidegger and the hermeneutic turn. In C. B. Guignon (Ed.), *The Cambridge companion to Heidegger* (pp. 170-194). Cambridge: Cambridge University Press.

Jablensky, A. (1993). The epidemiology of schizophrenia. *Current Opinion in Psychiatry, 6*, 43-52.

Jaspers, K. (1913/1963). *General psychopathology* (J. Hoenig & M. W. Hamilton, Trans.). Manchester: Manchester University Press.

Johnson, A. B. (1990). *Out of Bedlam.* New York: Basic Books.

Johnstone, E. C., Frith, C. D., Leary, J., & Owens, D. G. C. (1991). Concluding remarks. *British Journal of Psychiatry, 159(suppl. 13)*, 43-46.

Kaplan, B. (Ed.). (1964). *The inner world of mental illness.* New York: Harper and Row.

Kerr, N. J. (1990). The ego competency model of psychiatric nursing: Theoretical overview and clinical application. *Perspectives in Psychiatric Care, 26(1),* 13-24.

Kissling, W. (1992). Ideal and reality of neuroleptic relapse prevention. *British Journal of Psychiatry, 161*(suppl. 18), 133-139.

Kleinman, A. (1988). *The illness narratives.* New York: Basic Books.

Kondora, L. L. (1993). A Heideggerian hermeneutical analysis of survivors of incest. *Image: Journal of Nursing Scholarship, 25(1),* 11-16.

Krell, D. F. (1977). General Introduction: "The Question of Being." In D. F. Krell (Ed.), *Basic writings* (pp. 1-35). San Francisco: Harper San Francisco.

Krim, S. (1964). The insanity bit. In B. Kaplan (Ed.), *The inner world of mental illness* (pp. 62-79). New York: Harper and Row.

Laing, R. D., & Esterson, A. (1964). *Sanity, madness and the family.* Middlesex: Penguin Books Ltd.

Lally, S. J. (1989). Does being in here mean there is something wrong with me? *Schizophrenia Bulletin, 15(2),* 253-265.

Leary, J., Johnstone, E. C., & Owens, D. G. C. (1991). Social outcome. *British Journal of Psychiatry, 159*(suppl. 13), 13-20.

Lee, P. W. H., Lieh-Mak, F., Yu, K. K., & Spinks, J. A. (1993). Coping strategies of schizophrenic patients and their relationship to outcome. *British Journal of Psychiatry, 16* , 177-182.

Leininger, M. M. (1981). *Caring: An essential human need.* Thorofare, NJ: Charles B. Slack.

Lennane, J. (1993). The state of mental health (Letter). *The Bulletin, August 17*, 7.

Leonard, V. W. (1989). A Heideggerian phenomenologic perspective on the concept of the person. *Advances in Nursing Science, 11*(4), 40-55.

Levin, D. M. (1985). *The body's recollection of Being*. London: Routledge and Kegan Paul.

Liaschenko, J. (1989). Changing paradigms within psychiatry: Implications for nursing research. *Archives of Psychiatric Nursing, 3(3)*, 153-158.

Lieberman, J. A., Safferman, A. Z., Pollack, S., Szymanski, S., Johns, C., Howard, A., Kronig, M., Bookstein, P., & Kane, J. M. (1994). Clinical effects of clozapine in chronic schizophrenia: Response to treatment and predictors of outcome. *American Journal of Psychiatry, 151(12)*, 1744-1752.

Lieberman, J. A., & Sobel, S. N. (1993). Predictors of treatment response and course of schizophrenia. *Current Opinion in Psychiatry, 6*, 63-69.

Lipowski, Z. L. (1989). Psychiatry: Mindless or brainless, both or neither? *Canadian Journal of Psychiatry, 34*, 249-254.

Lorencz, B. (1991). Becoming ordinary: Leaving the psychiatric hospital. In J. Morse (Ed.), *The Illness Experience* . Newbury Park, CA: Sage.

Lovejoy, M. (1982). Expectations and the recovery process. *Schizophrenia Bulletin, 8(4)*.

Lowery, B. J. (1992). Psychiatric nursing in the 1990s and beyond. *Journal of Psychosocial Nursing, 30(1)*, 7-13.

MacDonald, N. (1964). Living with schizophrenia. In B. Kaplan (Ed.), *The inner world of mental illness* (pp. 173-184). New York: Harper and Row.

MacGilp, D. (1991). A quality of life study of discharged long-term psychiatric patients. *Journal of Advanced Nursing, 16*, 1206-1215.

Madjar, I. (1991). *Pain as embodied experience: A phenomenological study of clinically inflicted pain in adult patients*. Unpublished doctoral thesis, Massey University, Palmerston North, New Zealand.

Malmberg, A. K., & David, A. S. (1993). Positive and negative symptoms in schizophrenia. *Current Opinion in Psychiatry, 6*, 58-62.

Malone, J. A. (1990). Schizophrenia research update: implications for nursing. *Journal of Psychosocial Nursing, 28(8)*, 4-9.

Mayeroff, M. (1971). *On caring*. New York: Harper & Row.

McBride, A. B. (1990). Psychiatric nursing in the 1990s. *Archives of Psychiatric Nursing, 4(1)*, 21-28.

McEnany, G. W. (1991). Psychobiology and psychiatric nursing: A philosophical matrix. *Archives of Psychiatric Nursing, 5(5)*, 255-261.

McGhie, A., & Chapman, J. (1961). Disorders of attention and perception in early schizophrenia. *British Journal of Medical Psychology, 34*, 103-115.

McKeon, K. L. (1990). Introduction: A future perspective on psychiatric mental health nursing. *Archives of Psychiatric Nursing, 4(1)*, 19-20.

McLaren, N. (1992). Is mental disease just brain disease? The limits to biological psychiatry. *Australian and New Zealand Journal of Psychiatry, 26*, 270-276.

Minister of Health (1992). *Policy Guidelines to Regional Health Authorities*. Wellington: Department of Health.

Montgomery, C., & Webster, D. C. (1993). Caring and nursing's metaparadigm: Can they survive the era of managed care? *Perspectives in Psychiatric Care, 29(4)*, 5-12.

Morrissey, J. P., & Goldman, H. H. (1984). Cycles of reform in the care of the chronically mentally ill. *Hospital and Community Psychiatry, 35 (8)*, 785-793.

Morse, J. M. (1991). Negotiating commitment and involvement in the nurse-patient relationship. *Journal of Advanced Nursing, 16*, 455-468.

Morse, J. M., & Johnson, J. L. (1991). Toward a theory of illness: the illness constellation model. In J. M. Morse & J. L. Johnson (Eds.), *The illness experience* (pp. 315-342). Newbury Park, Ca: Sage.

Morse, J. M., Solberg, S. M., Neander, W. L., Bottorff, J. L., & Johnson, J. L. (1990). Concepts of caring and caring as a concept. *Advances in Nursing Science, 13(1)*, 1-14.

Mortimer, A. M. (1992). Phenomenology. Its place in schizophrenia research. *British Journal of Psychiatry, 161*, 293-297.

Moss, D. (1978). Brain, body, and world: Perspectives on body-image. In R. S. Valle & M. King (Eds.), *Existential-phenomenological alternatives for psychology* (pp. 73-93). New York: Oxford University Press.

Mulhall, S. (1990). *On being in the world: Wittgenstein and Heidegger on seeing aspects.* London & New York: Routledge.

Munhall, P. L. (1989). Philosophical ponderings on qualitative research methods in nursing. *Nursing Science Quarterly, 2(1)*, 20-28.

National Advisory Committee on Core Health and Disability Services, (1992). *Core Services 1993/94. A Report to the Minister of Health.* Wellington: Department of Health.

Norman, I., & Parker, F. (1990). Psychiatric patients' views of their lives before and after moving to a hostel: a qualitative study. *Journal of Advanced Nursing, 15*, 1036-1044.

O'Hagan, M. (1989a, August). *Consumer participation: The best thing that's happened to mental health for a long time.* Paper presented to the World Congress for Mental Health, Auckland, New Zealand.

O'Hagan, M. (1989b). *National Mental Health Consortium: The consumer report.* Wellington: Departments of Health & Social Welfare.

O'Toole, A. W., & Welt, S. R. (Eds.). (1989). *Interpersonal theory in nursing practice. Selected works of Hildegard Peplau.* New York: Springer.

Oiler, C. J. (1986). Phenomenology: The method. In P. L. Munhall & C. J. Oiler (Eds.), *Nursing research: a qualitative perspective* (pp. 69-84). East Norwalk: Appleton-Century-Crofts.

Oxman, T. E., Rosenberg, S. D., Schnurr, P. P., Tucker, G. J., & Gala, G. (1988). The language of altered states. *The Journal of Nervous and Mental Disease, 176(7),* 401-408.

Packard, N. J., Haberman, M. R., Woods, N. F., & Yates, B. C. (1991). Demands of illness among chronically ill women. *Western Journal of Nursing Research, 13(4),* 434-457.

Packer, M. J. (1985). Hermeneutic inquiry in the study of human conduct. *American Psychologist, 40(10),* 1081-1093.

Packer, M. J., & Addison, R. B. (Eds.). (1989). *Entering the circle: Hermeneutic investigation in psychology.* Albany: State University of New York Press.

Paterson, B. L. (1994). A framework to identify reactivity in qualitative research. *Western Journal of Nursing Research, 16(3),* 301-316.

Peden, A. R., & Staten, R. R. (1994). The use of the humanities in psychiatric nursing education. *Journal of Nursing Education, 33*(1), 41-42.

Peplau, H. E. (1989). Theoretical constructs: Anxiety, self, and hallucinations. In A. W. O'Toole & S. R. Welt (Eds.), *Interpersonal theory in nursing practice: Selected works of Hildegard E. Peplau* (pp. 270-325). New York: Springer.

Peterson, L. C., & Booth, C. (1988). Literature and music: An educational strategy in psychiatric mental health nursing. *Journal of Nursing Education, 27*(8), 374-377.

Peterson, R. (1982). What are the needs of chronic mental patients? *Schizophrenia Bulletin, 8(4).*

Pollock, L. C. (1989). *Community psychiatric nursing: Myth and reality.* Harrow, Middlesex: Scutari Press.

Pomare, E. W., & de Boer, G. M. (1988). *Hauora: Maori standards of health.* Special Report Series 78, Wellington: Department of Health and Medical Research Council.

Porter, R. (1987a). *A social history of madness*. New York: E.P. Dutton.

Porter, R. (1987b). *Mind-forg'd manacles*. London: Penguin Books.

Pothier, P. C. (1990). Toward a bio/psycho/social synthesis. (Editorial). *Archives of Psychiatric Nursing, 4(2)*, 77.

Rather, M. L. (1992). "Nursing as a way of thinking" - Heideggerian hermeneutical analysis of the lived experience of the returning RN. *Research in Nursing and Health, 15*, 47-55.

Rawlins, R. P., Williams, S. R., & Beck, C. K. (Eds.). (1993). *Mental health-psychiatric nursing* (3rd ed.). St Louis: Mosby.

Rawnsley, M. M. (1991). Chronic mental illness: The timeless trajectory. *Scholarly Inquiry for Nursing Practice, 5(3)*, 205-218.

Reinharz, S. (1983). Phenomenology as a dynamic process. *Phenomenology + Pedagogy, 1(1)*, 77-79.

Reynolds, W., & Cormack, D. (1990). *Psychiatric and mental health nursing: Theory and practice.* London: Chapman and Hall.

Roberts, G. (1991). Delusional belief systems and meaning in life: A preferred reality? *British Journal of Psychiatry, 159*(suppl. 14), 19-28.

Robinson, C. A. (1993). Managing life with a chronic condition: The story of normalisation. *Qualitative Health Research, 3(1),* 6-28.

Rogers, A., Pilgrim, D., & Lacey, R. (1993). *Experiencing psychiatry: Users' views of services.* London: Macmillan Press.

Romme, M. A. J., Honig, A., Noorthoorn, E. O., & Escher, A. D. M. A. C. (1992). Coping with hearing voices: an emancipatory approach. *British Journal of Psychiatry, 161,* 99-103.

Royston, M. C., & Lewis, S. W. (1993). Brain pathology in schizophrenia: developmental or degenerative? *Current Opinion in Psychiatry, 6,* 70-73.

Ruocchio, P. J. (1991). First person account: The schizophrenic inside. *Schizophrenia Bulletin, 17(2),* 357-360.

Sandelowski, M. (1986). The problem of rigor in qualitative research. *Advances in Nursing Science, 8(3),* 27-37.

Sandelowski, M. (1993). Rigor or rigor mortis: The problem of rigor in qualitative research revisited. *Advances in Nursing Science, 16(2),* 1-8.

Sandelowski, M. (1994). The use of quotes in qualitative research. *Research in Nursing and Health, 17,* 479-482.

Santopinto, M. D. A. (1989). The relentless drive to be ever thinner: A study using the phenomenological method. *Nursing Science Quarterly, 2(1),* 29-36.

Sass, L. A. (1988). The land of unreality: on the phenomenology of the schizophrenic break. *New Ideas in Psychology, 6(2),* 223-242.

Sass, L. A. (1990). Surrealism and schizophrenia: reflections on modernism, regression, and the schizophrenic break. *New Ideas in Psychology, 8(3)*, 275-297.

Sass, L. A. (1992a). *Madness and modernism: Insanity in the light of modern art*. New York: Basic Books.

Sass, L. A. (1992b). Heidegger, schizophrenia and the ontological difference. *Philosophical Psychology, 5(2)*, 109-132.

Sayre, J. (1990). Psychodynamics revisited: An object-relations framework for psychiatric nursing. *Perspectives in Psychiatric Care, 26(1)*, 7-12.

Schilpp, P. A. (1957). *The philosophy of Karl Jaspers*. New York: Tudor.

Schooler, N. R. (1994). Negative symptoms in schizophrenia: Assessment of the effect of risperidone. *The Journal of Clinical Psychiatry*, 55(5) (suppl), 22-28.

Sedgwick, P. (1981). Michel Foucault: The anti-history of psychiatry. *Psychological Medicine, 11*, 235-248.

Seeman, M. V. (1985). Clinical and demographic correlates of neuroleptic response. *Canadian Journal of Psychiatry, 30*, 243-245.

Seeman, M. V. (1986). Current outcome in schizophrenia: Women vs men. *Acta Psychiatrica Scandinavica, 73*, 609-617.

Sharma, T., & Murray, R. M. (1993). Aetiological theories in schizophrenia. *Current Opinion in Psychiatry, 6*, 80-84.

Siegler, M., & Osmond, H. (1966). Models of madness. *British Journal of Psychiatry, 112*, 1193-1203.

Siegler, M., & Osmond, H. (1974). *Models of madness, models of medicine*. New York: Macmillan Publishing Co.

Siegler, M., Osmond, H., & Mann, H. (1969). Laing's models of madness. *British Journal of Psychiatry, 115*, 947-958.

Simpson, R. B. C. (1989). Expressed emotion and nursing the schizophrenic patient. *Journal of Advanced Nursing, 14*, 459-466.

Sladden, S. (1979). *Psychiatric nursing in the community*. Edinburgh: Churchill Livingstone.

Sommer, R., & Osmond, H. (1983). A bibliography of mental patients' autobiographies, 1960-1982. *American Journal of Psychiatry, 140(8)*, 1051-1054.

Spinelli, E. (1989). *The interpreted world: An introduction to phenomenological psychology*. London: Sage.

Stein, L. I. (1987). Funding a system of care for schizophrenia. *Psychiatric Annals, 17(9)*, 592-593, 597-598.

Steiner, G. (1978). *Heidegger*. Hassocks, Sussex: The Harvester Press.

Stevens, J. R. (1992). Abnormal reinneravtion as a basis for schizophrenia: A hypothesis. *Archives of General Psychiatry, 49*, 238-243.

Stewart, D., & Mickunas, A. (1974). *Exploring phenomenology*. Chicago: American Library Association.

Strauss, J. S. (1989). Subjective experiences of schizophrenia: Toward a new dynamic psychiatry - II. *Schizophrenia Bulletin, 15(2)*, 179-187.

Strauss, J. S. (1992). The person - key to understanding mental illness: Towards a new dynamic psychiatry, III. *British Journal of Psychiatry, 161*(suppl. 18), 19-26.

Strauss, J. S., & Estroff, S. E. (1989). Foreword. *Schizophrenia Bulletin, 15(2)*, 177-178.

Swanson, K. M. (1993). Nursing as informed caring for the well-being of others. *Image: Journal of Nursing Scholarship, 25(4)*, 352-357.

Swanson-Kauffman, K., & Schonwald, E. (1988). Phenomenology. In B. Sarter (Ed.), *Paths to knowledge. Innovative research methods for nursing* (pp. 97-105). New York: National League for Nursing.

Szasz, T. S. (1971). *The manufacture of madness*. London: Routledge & Kegan Paul.

Tanner, C. A., Benner, P., Chesla, C., & Gordon, D. R. (1993). The phenomenology of knowing the patient. *Image: Journal of Nursing Scholarship, 25(4)*, 273-280.

Taylor, B. (1993). Phenomenology: one way to understand nursing practice. *International Journal of Nursing Studies, 30(2)*, 171-179.

Taylor, M. A. (1992). Are schizophrenia and affective disorder related? A selective literature review. *American Journal of Psychiatry, 149(1)*, 22-32.

Taylor, R. L., & Watson, J. (1989). Introduction. In R. L. Taylor & J. Watson (Eds.), *They shall not hurt* (pp. 1-9). Boulder, Colorado: Colorado Associated University Press.

Thorne, S. E. (1991). Methodological orthodoxy in qualitative nursing research: Analysis of the issues. *Qualitative Health Research, 1(2)*, 178-199.

Toombs, S. K. (1987). The meaning of illness: A phenomenological approach to the patient-physician relationship. *The Journal of Medicine and Philosophy, 12*, 219-240.

Torrey, E. F. (1988). *Surviving schizophrenia* (Rev. ed.). New York: Harper and Row.

Vaccaro, J. V., & Roberts, L. (1992). Teaching social and coping skills. In M. Birchwood & N. Tarrier (Eds.), *Innovations in the psychological management of schizophrenia* (pp. 103-114). Chichester: John Wiley & Sons.

Van Manen, M. (1989). By the light of anecdote. *Phenomenology + Pedagogy, 7*, 232-253.

Van Manen, M. (1990). *Researching lived experience.* London, Ontario: The Althouse Press.

Vellenga, B. A., & Christenson, J. (1994). Persistent and severely mentally ill clients' perceptions of their mental illness. *Issues in Mental Health Nursing, 15*, 359-371.

Watson, J. (1985). *Nursing: Human science and human care.* New York: National League for Nursing.

Watson, J. (1989). Human caring and suffering: a subjective model for health sciences. In R. L. Taylor & J. Watson (Eds.), *They shall not hurt* (pp. 125-135). Boulder, Colorado: Colorado Associated University Press.

Watson, P. (1991). Care or control. Questions and answers for psychiatric nursing practice. *Nursing Praxis in New Zealand, 6(2)*, 10-14.

Weissberg, M. (1991). Chained in the emergency department: The new asylum for the poor. *Hospital and Community Psychiatry, 42 (3)*, 317-320.

WHO Scientific Group on the Treatment of Psychiatric Disorders. (1991). *Evaluation of methods for treatment of mental disorders.* WHO Technical Report Series 812. Geneva: WHO.

Wiedl, K. (1992). Assessment of coping with schizophrenia. *British Journal of Psychiatry, 161*(suppl. 18), 114-122.

Wilkes, L. (1991). Phenomenology: a window to the nursing world. In G. Gray & R. Pratt (Eds.) *Towards a discipline of nursing* (pp. 229-246). Melbourne: Churchill Livingstone.

Wilson, H. S., & Kneisl, C. R. (Eds.). (1988). *Psychiatric nursing* (3rd ed.). Menlo Park, Ca: Addison-Wesley.

Wirshing, W. C., & Marder, S. R. (1993). Drug treatment in schizophrenia. *Current Opinion in Psychiatry, 6,* 85-89.

Wolf, Z. W., Giardino, E. R., Osborne, P. A., & Ambrose, M. S. (1994). Dimensions of nurse caring. *Image: Journal of Nursing Scholarship, 26(2),* 107-111.

Wolkin, A., Sanfilipo, M., Wolf, A. P., Angrist, B., Brodie, J. D., & Rotrosen, J. (1992). Negative symptoms and hypofrontality in schizophrenia. *Archives of General Psychiatry, 49,* 959-965.

Yank, G. R., Bentley, K. J., & Hargrove, D. S. (1993). The vulnerability-stress model of schizophrenia: Advances in psychosocial treatment. *American Journal of Orthopsychiatry, 63(1),* 55-69.

Yudofsky, S., Hales, R. E., & Ferguson, T. (1991). *What you need to know about psychiatric drugs.* New York: Grove Weidenfeld.

Zahniser, J. H., Coursey, R. D., & Hershberger, K. (1991). Individual psychotherapy with schizophrenic outpatients in the public mental health system. *Hospital and Community Psychiatry, 42(9),* 906-913.

Zimmerman, M. E. (1993). Heidegger, Buddhism, and deep ecology. In C. B. Guignon (Ed.), *The Cambridge companion to Heidegger* (pp. 240-269). Cambridge: Cambridge University Press.