MENTAL ILLNESS:
Towards an Understanding of the Experience of Treatment and Diagnosis

by

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ABSTRACT

This thesis investigates and describes the experience of three individuals in the process of being diagnosed and treated for a mental illness. Essentially, the study was interested in how one defines and understands his or her 'life-world' within the context of a mental illness and how this affects one personally and professionally. Three individuals, one female and two males, ranging in age from 18- 34 years were recruited into the study by contacting local psychiatrists. A qualitative methodological framework combined phenomenology, which explores lived human experiences, with hermeneutics, which seeks to explain how meaning is constructed, in examining the phenomenon of mental illness. A series of tape-recorded interviews using a semi-structured interview format provided the participant's data. In describing the experience of diagnoses and treatment of a mental illness, participants identified a number of issues: self-concept; stigma; fears; losses and frustrations; isolation and relationship dynamics; and insights and awareness. In personal reflections regarding the interview process, participants described the interviews as a positive experience, gaining benefits such as new insights, awareness, and a sense of closure with their illness. Implications regarding a phenomenological approach to the practice of counseling are discussed.

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CHAPTER 1

INTRODUCTION

Within the medical model, the phenomenology of adolescent mental illness has focused on clinical characteristics, epidemiology, comorbidity and treatment factors (Carlson, 1981; Geller & Luby, 1997; Hornstein & Putnam, 1992; Lewinsohn, Klein, & Seeley, 1995; Riddle, Scahill, King & Hardin, 1990). The identification, prevalence, symptomatology (e.g., depression, suicide, substance abuse, conduct disorders) and associated problems (i.e., such as poor academic performance, impaired social relations and social functioning) observed in adolescent mental illness are well documented in the literature (Kutcher & Marton, 1989; Pinto & Whisman, 1996; Stein, Elliott, & McKeough, 1982).

Another theory on the development and presence of adolescent mental illness, or psychiatric illness (these terms 'mental illness' and 'psychiatric illness' will be used interchangeably) focuses on adolescent psychiatry as a response to mental illness produced by cultural and societal factors (Fabrega & Miller, 1995; Hill, & Fortenberry, 1992). This perspective sees adolescent psychiatry as a response to human problems caused by social, political, and economic factors culminating in stresses specific to adolescence (Fabrega & Miller 1995).

Irrespective of the different theories (i.e., medical and social) and focus of adolescent psychiatry, the "phenomenological experience" of those diagnosed and treated with a psychiatric illness is limited in the research. The concept of "phenomenological experience" has been described as a means of helping a person "...understand what it means to be who they are in the world [and] fulfillment of a person's human nature [so they] can become fully who they are" (Van Manen, 1990, p. 12).

Understanding oneself and one's place in the world is closely related to the concept of identity formation in adolescents. This is considered a major developmental task for adolescents who are questioning who they are and how they fit into their world "...attempting to achieve independent status of a young adult" (Arnstein, 1986, p. 797). This period of identify formation (by means of self- exploration) in pursuit of understanding one's place in the world is often described as a transitional period for adolescents that can result in much ambivalence and uncertainty about one's role and place in society (Hughes & Brand, 1993).

Consider the aforementioned facts: adolescent mental illness is associated with detrimental consequences such as suicide and impaired social functioning; adolescence is a transitional period of identity formation and self –exploration that can result in much turmoil and role confusion; and limited research on the phenomenological experience of adolescent mental illness all warrant investigation of how mental illness is experienced by a youth population.

The practical significance and purpose of this study is that investigation of participants' phenomenological experience of mental illness can result in a positive experience or possible change (if desired) for participants. The experience of sharing the participants stories and interpretations of mental illness may lead to new and helpful insights such as "...hope, increased awareness, moral stimulation, insight, a sense of liberation, [or a] certain thoughtfulness..." (Van Manen, 1990, p. 162).

Participants may experience increased awareness of their mental illness through redefining their original views, adding meaning to their lives, and understanding the role that mental illness has played in their lives. Furthermore, increased awareness of the impact of a psychiatric diagnosis on career aspirations, familial relations, and ultimately their place in the world, may prompt participants to critically examine the possible need for acceptance, or change, in their understanding of what it means to experience and live with a mental illness.

From a theoretical stance, further research on adolescent mental illness is needed if gains are to be made in the practice and delivery of adolescent mental health. This can occur by examining the knowledge and insight offered by youths regarding their own mental illness experience. Ultimately, successful diagnoses and treatment of a mental illness must be studied from an experiential perspective since experience is the first place for any human investigation.

THESIS STATEMENT

The primary purpose of this thesis was to investigate and describe the experience of three individuals in the process of being diagnosed and treated for a mental illness by a licensed practicing psychiatrist. The investigator examined participants' experience of a mental illness in the context of their daily life or "life world" with respect to both their personal and professional selves. Investigation of this phenomenon provides a better understanding of the experience of diagnoses and treatment for a mental illness from the perspective of the three individuals who participated in this study. Essentially, the study was interested in how one defines and understands themselves within the context of their illness and their "life world." The experience of a mental illness in terms of its impact on one's self-concept, personal relationships, professional development and everyday social functioning are all points of interest in examining the phenomenon of mental illness.

CHAPTER 2

LITERATURE REVIEW

Mental illness, in the form of depressive symptomatology (i.e., sad affect, sleep and or appetite disturbance, negative or self-critical attitudes) is a common psychological disturbance experienced in youth and adult populations alike (Beck, 1976; Kandell & Watson, 1989). The past decade or so has witnessed an increase in the identification of adolescent depressive symptoms and suicide (Dr. V. Kusumakar, personal communication, October 21, 1998). Depressive symptomatology in a youth population has been associated with deficits in academic performance, interpersonal relations, social functioning and difficulties with family relations (Barnett & Gotlib, 1988; Harrington, Fudge, Rutter, Pickles, & Hill, 1990; Kandel & Davies, 1986; Kutcher & Marton, 1989). Other detrimental consequences of depressive disorders in youths include conduct disorders, substance abuse, and suicide (Kutcher & Marton, 1989; Pinto & Whisman, 1996). Furthermore, depressive symptomatology is a risk factor for the development and chronicity of future depressive disorders (Chess, Thomas, & Hassibi, 1983; Harrington et al., 1990; Stein, Elliot, & Mckeough, 1982).

Within the medical model, the phenomenology of adolescent mental illness has focused mainly on clinical characteristics, epidemiology, comorbidity and treatment factors (Carlson, 1981; Geller & Luby, 1997; Hornstein & Putnam, 1992; Lewinsohn, Klein, & Seeley, 1995; Riddle, Scahill, King & Hardin, 1990) often attributed to biological and genetic factors (Duman, Heninger, & Nestler, 1997). Other theories influencing the development and presence of adolescent psychiatry include cultural and societal factors (Fabrega & Miller, 1995; Hill & Fortenberry, 1992).

Fabrega and Miller (1995) argue that the surge of adolescent psychiatric illness over the past two decades is more a product of historical and cultural factors inherent in a contemporary industrial Anglo-American society than a product of genetic or bio-genetic causes. They purport that adolescent psychiatry evolved partly in response to human problems being seen as influenced by social, political, and economic factors that culminated in stresses specific to adolescence (1995). This view has resulted in a heightened awareness of adolescent psychiatry as a distinct and prevalent area in need of research and treatment by the medical field (1995).

Similar to Fabrega and Miller's (1995) account of adolescent psychiatry, Hill and Fortenberry (1992) argue that the apparent emotional and psychological turmoil experienced by adolescents is a product of what Rittenbaugh (1982) defines as a "culture-bound syndrome: a constellation of symptoms which has been categorized as a disease" (1982, p. 347). Characteristics associated with the identification of this syndrome include: 1) it cannot be understood apart from its specific cultural or sub- cultural context; 2) the etiology summarizes and symbolizes core meanings and behavioral norms of the culture; 3) diagnosis relies on culture-specific technology, ideology, and successful treatment is experienced only by participants in that culture (Rittenbaugh, 1982, p. 347).

Hill and Fortenberry (1992) attribute the medicalization of adolescence in American society, which has resulted in pathologizing the turmoil associated with this developmental stage, to an "...apparent epidemic of adolescent psychiatric illness" (1992, p. 78). They suggest "...that the creation of adolescence as an age-based pathological condition contributes to a masking of factors that contribute to threats to health in a highly differentiated complex society" (1992, p. 78). Along with Fabrega and

Miller (1995), Hill and Fortenberry attribute much of adolescent mental illness to the influence of cultural and social phenomenon rather than strictly to biogenetic factors.

There are opposing views, for example, Offer and Schonert- Reichl (1992) argue against the theory that sees adolescence as a period of enhanced psychopathology. They challenge a number of commonly held myths associated with the developmental stage of adolescence, including the myth that adolescence is a time of 'severe emotional upheaval'. They cite the fact that 80% of adolescents do not experience emotional turmoil and, thus manage this developmental stage quite effectively (p. 1003). Other myths debunked by Offer and Schonert-Reichl include: 1) normal adolescent development is tumultuous; 2) puberty is experienced as a negative event; 3) adolescence is a time of increased risk for suicide; and 4) adolescent thought is childlike (p. 1004-1005).

However, Hughes and Brand in 'letters to the editor' (Hughes & Brand, 1993) claim that Offer and Schonert-Reichl (1992) overstated their case about the "myths of adolescence." Hughes and Brand assert that there is a lot of truth in these "myths." They state that 1) severe turmoil is inherent and therefore to be expected in normal adolescent development; 2) extreme emotionality is a normal part of all adolescent development; 3) puberty is nearly always a negative event for adolescents; 4) adolescent suicide continues to increase at an alarming rate; and 5) adolescent thought remains very childlike until adolescents achieve adulthood (1993, p. 1077).

The phenomenon of adolescence as a developmental stage of emotional and psychological turmoil and the prevalence of adolescent symptomatology such as depression and suicidality have been well addressed by the literature (Kutcher & Marton, 1989; Pinto & Whisman, 1996). We know a lot about the epidemiology, natural course, comorbidity, neurobiology and treatment of adolescents with a psychiatric illness. What we do not know, and what is ill-treated within the literature, is the actual experience of diagnosis and treatment of a psychiatric illness as experienced by a youth population. Only a few studies have addressed the use of a phenomenological approach in the research of psychopathology or mental illness, and none of these address adolescent mental illness specifically (Jaspers, 1968; Stein et al., 1982; Varghese, 1988).

In a paper titled *Phenomenology of Psychotherapy*, Jaspers (1968) discussed the difference between the subjective and objective experience of "psychic events," claiming that the subjective experience of psychopathology is best studied by a phenomenological approach. He purports that this approach is "...one which will isolate [and] make abstractions from related observations, [and] present as realities only the data themselves without attempting to understand how they have arisen." (1968, p. 1318). Jaspers further states this as "...an approach which only wants to see, not to explain" (p. 1318). Psychopathological symptoms studied within a phenomenological framework include hallucinations, delusions, and emotional disturbance; however, a framework in the study of mental illness is still lacking. More specifically, there is little said of phenomenological work examining the experience of adolescent mental illness.

Varghese (1968) also examined the efficacy of a phenomenological approach in psychotherapy. He concluded that a Husserlian phenomenological approach to psychopathology and psychotherapy allowed for a phenomenological understanding of the essence of one's being and existence (p. 401). This is believed to occur as a result of the therapeutic relationship between a client and therapist whereby the therapist remains open-minded, relinquishing "...preconceived ideological notions...by getting into the patient's [mind], be where he is, and indeed share his paradigm" (p. 401). The "corrective emotional experience" of psychotherapy that allows clients to experience themselves differently, resulting in therapeutic change, is a function of the therapist's ability to maintain this open, non-ideological frame of mind. He states that "...change results not merely from experiencing anew but rather in the experience of error" (1988, p. 401).

In consideration of the different theories of adolescent mental illness, the personal impact of a psychiatric illness, and the absence of phenomenological research on adolescent mental illness, investigation of this phenomenon from the perspective of the consumer, those individuals diagnosed and treated for a mental illness, is warranted. The current study adopts a phenomenological hermeneutic methodology to investigate participants' experience of diagnoses and treatment of a mental illness.

The researcher's original intent was to interview an adolescent population; however, recruitment complications arose which prevented the execution of this plan. The alternative offered and employed here was to interview individuals who had had experience with a mental illness during their youth (i.e., adolescence). Consequently, participants recruited for this study ranged in age from 18 to 33 years old. The participants' mental illness, as experienced in their youth, composes the data in this study. Follow-up data for two participants who still exhibited illness symptoms, during and after the research interviews is also included.

It was hoped that implementation of a phenomenological methodology would result in a deeper understanding and appreciation of the experience of mental illness for participants, the current investigator and future examiners. Although it is not the main purpose of the study, an additional outcome would be the emancipation of the stigmatizing effects of adolescent mental illness. Having presented the literature in support of the current study, I now present the methodological framework, phenomenology and hermeneutics, used to investigate participants' experience of the diagnosis and treatment of a psychiatric illness with a focus on the meaning of this experience for the participants.

CHAPTER 3

METHODOLOGY

As a methodology framework, phenomenology and hermeneutics were used to examine study participants' experience of mental illness. An examination of the assumptions that underlie a phenomenological research methodology will help to elucidate the rationale for adopting this approach in the current study. Before elaborating on these assumptions it is necessary to be aware of the distinction between the "phenomenology" and "hermeneutics."

Introducing Phenomenology

Edmund Husserl, a "pioneer" in the philosophy of science; was influenced by philosophers such as Descartes and Hegel in developing a phenomenological approach to studying and understanding human science. Although Husserl's radical approach to science was badly received in his time, his works are now widely accepted as an appropriate framework for researching social human phenomenon (Moustakas, 1994). Moustakas quotes Husserl: "this being 'in love with philosophy' captures me also and evokes a desire to employ phenomenology in discoveries of knowledge and in theories and applications of human science" (1994, p. 25).

Kockelmans (as cited in Moustakas, 1994) purports that the term "phenomenology" was used as early as 1765 in the writings of Kant, but that it was Hegel who was responsible for a well constructed definition. According to Hegel, "...phenomenological referred to knowledge as it appears to consciousness, the science of describing what one perceives, senses, and knows in one's immediate awareness and experience" (1994, p. 26).

Husserl developed the concept of *Epoche*, a Greek term that means "...to stay away from or abstain" (Moustakas, 1994, p. 85) inherent in phenomenological philosophy. In the practice of phenomenological research, *Epoche* means to be free of suppositions, prejudgments, biases, or preconceived ideas, and to value the intuitions and knowledge of the self in discovering the nature and meaning of phenomena as they appear in their own essence (1994, p. 26).

The phrase "phenomenon" originates from the Greek word phaenesthai meaning "...to flare up, to show itself, to appear" (Moustakas, 1994, p. 26). Taken from phaino, "phenomenon means to bring to light, to place in brightness, to show itself in itself, the totality of what lies before us in the light of day" (Heidegger, as cited in Moustakas, 1994, p. 26). The maxim of phenomenology has been described as "to the things themselves" and as "that which appears provides the impetus for experience and for generating new knowledge" (1994, p. 26). In other words, "phenomena are the building blocks of human science and the basis for all knowledge" (p. 26).

Phenomenology is concerned more with how one "...experiences the world" (Van Manen, 1990, p. 5) and less concerned with analytical interpretation. This is not to say that phenomenology is not interested in understanding the social reality experienced by persons; however, phenomenology says that these social realities need not be interpreted beyond interpretations offered by those studied.

Introducing Hermeneutics

In contrast to phenomenology, hermeneutics is defined as the study of the interpretation of texts whereby an understanding and meaning of the "object" being defined can be obtained (Kvale, 1996). Relevant to the study of social inquiry, hermeneutics attempts to make sense of dialogue and text produced out of research with the intent of understanding it "from the inside" (Van Manen, 1990). It is concerned with an understanding and interpretation of both the text (dialogue) and the process by which particular text has been derived.

Hermeneutic interpretation purposes that meaning is constructed by a concept known as the hermeneutical circle, which includes seven canons of interpretation (Kvale, 1996, pp. 47-50). The first canon of interpretation, called "circulus fructuosis" or "spiral," involves a continuous back and forth of exploration of one's data, in which one pieces the parts together with the whole in an attempt to eventually arrive at some meaningful interpretation. With respect to research interviews, for example, one would first read and analyze interviews to gain some general meaning, then progress to more specific themes or meanings, and end by examining a more global meaning of the parts.

The second canon, good gestalt, "...is an inner unity of text free of logical contradictions" (1996, p. 48) that results from a completed interpretation of meaning. Relevant to research interviews, interpretations of meaning halt when some meaning or sensible pattern arises within the data. The third canon involves a "testing" of part interpretations against the more global meanings of the data. In research interview data, this would translate into a comparison between interpretations gained from single statements and more global meanings derived from part interpretations.

The fourth canon is concerned with the "autonomy of the text," which means to be understood in its own essence, free of any prejudgments or biases destructive to the original framework in which the themes were developed. The fifth canon is concerned with "knowledge about the theme" of the text. In conducting qualitative research interviews like those in the current study, one must be familiar with the major theme/themes to avoid missing any underlying or hidden meanings. This requires sensitivity to the "nuances" of meanings expressed and the different contexts in which meanings arise.

The sixth canon of interpretation requires that the text is not presuppositionless. Although this is in direct contradiction to the concept of Epoche, the hermeneutic circle of canons states that the interpreter "cannot jump outside the tradition of understanding he or she lives in" (Kvale, 1996, p. 49). Nonetheless, efforts should be made to be aware and make known any presuppositions so as to guard against any bias in the interpretations of meaningful text. Kvale (1996) warns about the need for a consciousness of presuppositions when using the interview as a research method, so that interviewer and interviewee do not "co-determine the results" (1996, p. 49). The seventh canon purports "...that every interpretation involves innovation and creativity" (p. 49). In other words, "every understanding is a better understanding" (1996, p. 49). This involves a constant going between the immediate and not so immediate interpretations searching for deeper and different meanings buried within the data.

Having defined phenomenology and hermeneutics, I will now discuss the use of these two concepts as a single methodological approach employed in this study.

Phenomenology and Hermeneutics: Methodological Approach

Van Manen (1990) discusses the assumptions of phenomenological hermeneutic research of human science in terms of what it is and is not. In terms of what it is, "phenomenological research is the study of lived experience" as experienced by persons. (1990, p. 9). Being concerned with the depth and meaning of experience, phenomenological research asks, "what is this or that kind of experience like?" (p. 9). Phenomenology is the "explication of phenomenon as they present themselves to consciousness" (p. 9). Anything that presents itself to a person's consciousness, whether it is "real or imagined", is of value to phenomenological research. There is a belief that consciousness is the only path accessible to humans in order to be connected within their world.

Another assumption of phenomenological hermeneutic research is the study of the "essence" of human experience. One perspective of the concept of "essence" is its concern with the essential quality or substance of a person's experience. Knowledge of the very essence of a human being is believed to occur if it "...reawakens or shows us the lived quality and significance of the experience in a fuller or deeper manner" (Van Manen, 1990, p. 10). Phenomenological research is also "... the description of the experiential meanings we live as we live them" (p. 11). There is an attempt to "...describe and interpret...meanings..." [as they are lived and experienced] in our everyday existence [and] life world" (p. 11).

Phenomenological research is the "human scientific study of phenomenon." It is a systematic, explicit, self-critical and intersubjective study of how particular phenomena are experienced (Van Manen, 1990, p. 13). It is "systematic" in that it utilizes specific types of questions and communication patterns to elicit the lived experience of its subjects. It is "explicit" in that it attempts to elucidate the process by which meaning is structured within a person's lived experience. Phenomenological research is self-critical in that it continuously appraises its own "goals and methods" in an effort to critically examine the robustness or weakness of its "approaches and achievements" (p. 11).

Lastly, "it is 'intersubjective' in that it appreciates the need for the other [e.g., the reader or researcher] in forming a 'dialogic relation' with the phenomenon [of study], and thus validates the phenomenon as described [by a participant]" (p. 11). Since the content of phenomenological research is about the structure of meaning of the lived human world, it has been given the term "human science", and thus can be studied within a human scientific (phenomenological) paradigm (1990).

Phenomenological research has also been described as the attentive practice of thoughtfulness (Van Manen, 1990, p. 12). Heidegger describes thoughtfulness as "...a minding, a heeding, a caring attunement–a heedful, mindful wondering about the project of life, of living, of what it means to live a life" (1962, p. 11). Another assumption of phenomenological research is its "search for what it means to be human." It is concerned with helping a person "...understand what it means to be who they are in the world" (1990. p. 12). Its overall goal in research is fulfillment of a person's human nature so that they can "...become fully who they are." (p. 12)

One last assumption of phenomenological research outlined by Van Manen (1990) is its "poetizing activity." Like poetry, phenomenological research is without a specific conclusion or 'summative results' gathered by data analyses as in logical–empirical research. Merleau- Ponty (1973) described phenomenological research as a "...poetizing project: [that] tries an incantative, evocative speaking, a primal telling, wherein we aim to involve the voice in an original singing of the world" (p. 12).

Another way of thinking about what constitutes phenomenological research is to consider what it is not. I will briefly present four nondescriptive qualities of phenomenological research as outlined by Van Manen (1990). First, it is not an empirical analytical science concerned with facts that are generalizable to a particular phenomenon or population. Secondly, phenomenological research is "not mere speculative inquiry in the sense of unworldly reflection" since it studies phenomenon from the perspective of lived experience that goes beyond "sheer universality" (p. 23). Thirdly, it is "neither mere particularity, nor sheer universality" in that it mediates between an interest in "concreteness", differences, and uniqueness (i.e., particularity) and an interest in the "essentiality" or "difference that makes a difference" (Van Manen, 1990, p. 23). Lastly, phenomenological research "does not problem-solve" in the same sense that quantitative research does to establish norms, solutions, and generalizability. Phenomenological research is concerned with questions of "experience and meaning" versus questions of problem solving, and thus, is unique and different from the purpose and design of logical empirical research.

Concepts such as "experience" and "meaning" originates out of Schutz's phenomenological sociological framework for understanding human experience. The phenomenological definition of "experience" has been described as:

> The basic starting point of all phenomenological consideration is the essential actual, or immediately vivid, experience, that is, the subjective, spontaneously flowing stream of experience in which the individual lives and which, as a stream of consciousness, carries with it spontaneous linkages, memory traces, ect., of other, prior, experiences. Experiences become subjectively meaningful experience only by an act of reflection in which an essentially actual experience, in retrospect, is consciously apprehended and cognitively constituted. In the course of his life, a person compiles a stock of experience, which enables him to

> define the situations in which he finds himself and to guide his conduct in them (Wagner, 1970, p. 318).

The phenomenological definition of meaning has been described as:

> Established, in retrospect, through interpretation. Subjective meaning is that meaning which a person ascribes to his own experiences and actions. Objective meaning is the meaning imputed to the conduct of another person by an observer. All human conduct appears in a subjective meaning context. The meaningful self –interpretation of conduct consists in relating specific experiences to other experiences in the light of one's interest and motives involved. By contrast, interpretation of the conduct of another person consists in relating the observed conduct to an objective meaning context, consisting of preestablished generalized and typified conception. (Wagner, 1970, p. 320).

The phenomenological term, "life world" originates in the works of Alfred Schutz and describes and defines lived human experiences. Simply put, life world is "...the whole sphere of everyday experiences, orientations, and actions through which individuals pursue their interest and affairs by manipulating objects, dealing with people, conceiving plans, and carrying them out" (Wagner, 1970, p. 15). Schutz's phenomenological philosophy of the "life world" constitutes a sociological framework based on phenomenological considerations (Wagner, 1970). "Life world" or "world of daily living" is defined as:

> The total sphere of experiences of an individual which is circumscribed by the objects, persons, and events encountered in the pursuit of the pragmatic objective

> of living. It is a 'world' in which a person is 'wide- awake' and which asserts itself as the 'paramount reality' of his life (Wagner, 1970, p. 320)

Schutz's view on the "life world" or "world of daily life" refers to an "intersubjective world" existing before our birth which has been experienced and interpreted by our ancestors as an "organized world" that later becomes passed on as our own experiences and interpretations (Wagner, 1970, p. 72). Thus, all our perceptions and interpretations of our world result from a multitude of experiences passed on by influential others such as our parents and educators (1970).

Schutz believed that the "life world" frames how individuals operate within their world in relation to themselves and others (Wagner, 1970). Secondly, he believed that the "...content and sequence of [individuals] experiences are unique and that... no two persons could possibly experience the same situation in the same way" (p. 15). More importantly, that an individual enters into their situations with his or her own "...purposes and objectives in mind, and appraises it accordingly; and that these purposes... are rooted in [one's] past, in [one's] unique life history" (p. 15).

Another aspect of the "life world" concept is the means by which individuals orient themselves in life situations. This is described as one's "store of knowledge" or "stock of knowledge on hand" (Wagner, 1970, p. 15). Schutz believed that individuals could not interpret their experiences and observations, define their present situations, or make plans for the "next minutes" without consulting their stock of knowledge (p. 15).

This stock of knowledge can contain relevant, marginal, and even irrelevant elements. However, specific elements within one's stock of knowledge can be "...precise and distinct, others vague or obscure" (Wagner, 1970, p. 15). One's stock of knowledge is never without contradictions, however, as long as contradictory and incoherent information is not present to awareness; simultaneously persons "...may remain blissfully unaware of themselves" (p. 16). Likewise, a pragmatic or realistic frame of mind can prevent individuals from systematically and logically examining clear knowledge about situations or objects that go "...beyond the requirements of [their] practical operations or plans, which, frequently, assume routine character" (p. 16).

Phenomenological theory sees each individual as constructing their "own world," using what is offered by others in his or her world (Wagner, 1970, p. 16). Thus, the life world is seen as a social world that is already prestructured for an individual. Schutz believed there is a strong 'interplay' between individuals' efforts to understand their social world and the "cognitive prestructurization" of this world itself (p. 16). Schutz was strong on the subjective meaning of an individual's membership within his or her community (p. 17). He believed this meaning originated from one's efforts to "...achieve a definition of his [or her] own place, his [or her] general role...[in ones'] community (p. 17). He demonstrated that the most socially stereotyped cultural ideas exist only in the minds of those that absorb them, interpret them based on their own experiences, "...and give them a personal tinge which the reporting anthropologists so often ignore" (p. 17).

Schutz also spoke of the life world as a "typified world," and claimed that individuals could not account for their experiences without resorting to "typifications" (Wagner, 1970). The act of naming is believed to constitute a typification. Schutz discusses typifications extensively, including typifications of objects, animals, and experience. Experience typification is the most relevant for the current study.

Experience typification talks about forms of recognition and identification, including even the real objects in the outer world, as a product of "...generalized knowledge of the type of these objects or the typical style in which they manifest themselves" (p. 118). In other words, each experience is unique and the same experience that "recurs" is not the same, simply because it does re-occur (p. 118).

"Meaning" is another pertinent concept in phenomenology addressed by Schutz (1970). He speaks about "acts of reflective attention" as of "...major importance for the study of meaning" (p. 63). Living experiences are "[apprehensible], distinguished, brought into relief, marked out from one another...and these experiences...become objects of attention as constituted experiences" (p. 63). This "act of attention" [presupposes] an experience that is already past, whether the attention in question is "reflective" or "reproductive." The understanding of past, "elapsed" or "discrete" experiences are believed to occur by an act of attention versus "living" through the experiences. Thus, only a past experience is thought to be meaningful. This is because only a past experience is subject to a "retrospective glance" that is completed and done with. In other words, "...only the already experienced is meaningful, not that which is being experienced" (p. 63).

The origins of phenomenological ideology and a description of the assumptions of what is, and is not phenomenological research, elucidate the relevance of adopting a phenomenological methodology in the study of an individual's mental illness experience. I believe that issues related to mental illness; how this is experienced and perceived by individuals, the impact of mental illness on one's emotional and psychological development, and an individual's experience and perceptions of mental health services are best studied by this approach.

Providing individuals with the opportunity to share their stories and describe their experience with mental illness can only serve to enhance our knowledge and practice of mental illness in a youth population. I believe this method of investigation will assist mental health professionals, and researchers alike to improve the practice and delivery of mental health services for a youth population. However, this is more of a secondary benefit, albeit a desirable one, in the current study with participant's experience of a mental illness as the primary purpose and focus.

In summary, it is hoped that research participants will gain a deeper understanding and meaning of their mental illness experience. Insights and meaning resulting from their participation can lead to a better understanding or interpretation of their illness, and thus a better means of coping and managing this experience.

Before discussing the specific research method in the study of participants' mental illness experience, a brief discussion of literature pertinent to qualitative research methods and analysis is presented. General principles on coding analysis are also presented.

Qualitative Research: Phenomenology

Because the current study is qualitative in nature, a word on the application of qualitative research with respect to a phenomenological framework is warranted. In a paper titled "*A phenomenological Perspective on Certain Qualitative Research Methods*", Giorgi (1994) argues for a phenomenological approach as an alternative framework in the application of qualitative research stating "...that a deepened understanding of phenomenological philosophy can provide the alternative framework that many authors have been seeking" (p. 190). Giorgi describes the research era as "...living through a pioneering of methodology" (p. 190). The search for meaningful but rigorous methods of doing human research has resulted in an abundance of articles and books on qualitative methods since the publication of the first grounded theory text by sociologists Glaser and Strauss (1967, as cited in Giorgi, 1994). In a paper on competing qualitative research strategies (i.e., descriptive versus interpretative methods), Giorgi (1992) claims that the qualitative research movement is about twenty years old (approximately thirty years now) and "... probably has sufficiently established itself so that its status as a submovement in science is irreversible" (1992, p. 120).

A phenomenological methodology is described as a "comprehensive" beginning from a place of consciousness that allows whatever is perceived to present itself exactly as it is (Giorgi, 1994, p. 190). It is concerned with the experience, exactly as it is experienced, relinquishing pre-judgments or previous knowledge of the phenomenon (Giorgi, 1971, I, p. 9). It aims to comprehend the phenomenon exactly as it is described, attending to the origins or foundations with "an emphasis on the perspectivity through which all phenomena are known" (Giorgi, 1971, I, p. 10).

Girogi (1971) describes the phenomenological method as a "process of intuition reflection and description" (1971, I. p. 10) by which one should first focus on what is presented as it is, and only later ask specific questions about the phenomenon. This allows the researcher to see what emerges rather than selecting aspects of desire or those he wishes to manipulate, or defining the phenomenon in terms of his manipulations. Thus, the task for a phenomenological researcher is not to predict or surmise in advance what a certain reality is for research participants, but to describe the reality as perceived and explained by participants. This allows for the discovery of realities outside the researcher's domain (Giorgi, 1994).

In part two of "*Phenomenology and Experimental Psychology*" Giorgi (1971) states that the essential question in the study of human science "is not how do we measure phenomena, but rather, what do the phenomena mean?" (p. 21). He recognizes that the way to understand human experience is not the same way we might understand physical or biological reality (p. 11). In other words, "a method proper to the subject matter is required" (p. 10). The focus is on the meaning or essence of an experience for a research participant.

Another important factor considered in the application of qualitative phenomenological research is the context. Phenomena appear in a context which no doubt affects how it may, or may not be understood, and what meaning is derived. Thus, a certain phenomenon cannot be studied, or understood outside its context, and if removed will probably take on a new and different meaning (Giorgi, 1971, part II).

In speaking to the phenomenological methods and implementation of concrete research methods, Girogi (1994, pp. 206-207) summarizes the method into three interrelated steps: 1) description of the phenomena to be studied has to be described exactly as is without adding or subtracting from what is perceived and described; 2) phenomenological reduction whereby the researcher relinquishes (brackets) any or all preconceived ideas about the studied phenomena; 3) a search for the essences of the phenomena that arise via the descriptive and phenomenological reduction method. This results in the creation of invariant characteristics and co-existing relationships forming the structure of the phenomenon.

Modes of Understanding Qualitative Research: Kvale

Kvale's (1996, pp. 29-36) identifies a mode of understanding in the qualitative research interview. I will briefly outline each of these stages, since they were all relevant to the research interviews conducted in the current study: 1) "life world" is the lived world of the research participants as they experience it. The researcher is concerned with describing and understanding central themes which participants experience and live toward; 2) meaning is the second stage in the mode of understanding research interviews, attempting to understand and interpret the central themes within participants' life world experience; 3) a qualitative approach, and thus a qualitative knowledge base, is the goal for the research interviewer--quantifying results is not an issue; 4) a fourth mode of understanding presents descriptive accounts of participants' experiences as lived out in their 'life world' and as expressed in normal everyday language; 5) specificity includes descriptions of specific situations and actions--general opinions are not included; 6) deliberate naivete is openness to new and unexpected phenomenon without any a priori ideas or assumptions of what to expect; 7) a seventh mode of understanding is to focus on specific themes that are neither strictly structured nor entirely non-directive; 8) ambiguity in participants' statements can occur and is somewhat reflective of real contradictions in their life worlds; 9) change in the description or meaning of a participant's experience can occur as a result of the research interview, whereby new insights or awareness surface; 10) the sensitivity of the interviewer can affect and change statements made on the same themes, depending on their sensitivity to, and knowledge of the interview topic;

11) "interpersonal situation" states that knowledge is produced via the interpersonal interaction in the interview; 12) a positive experience is one goal that researchers hope to accomplish whereby new insights into a participant's life emerge.

Concept of Coding

The specific mode of analysis applied in the current study is a strict coding procedure with various stages of application. Before discussing this specifically, I will present some literature on the use and process of coding in qualitative research. Coffey and Atkinson (1996) speak about the "fruitlessness" of seeking out one perfect method of analysis, suggesting that there is no one single right way to analyze qualitative research, but rather many ways to make sense of qualitative data. This does not mean choosing haphazardly the first method that presents itself, but rather for one to explore and study the various methods in an attempt to choose the best method for the specific research need. One should be critical and scrupulous in deciding on one method over another.

Coding can be thought of as organizing, retrieving and interpreting data (Coffey & Atkinson, 1996, p. 27). Miles and Huberman (1994) state that coding "constitutes the stuff of analysis [allowing one to] differentiate and combine the data you have retrieved and the reflections you make about this information" (1994, p. 56). Coding prepares the stage for identification of meaningful data in preparation of interpretation and conclusion. However, one should note that true phenomenological research is not necessarily concerned with any specific conclusion—"what is is what is." Miles and Huberman define codes as:

> Tags or labels for assigning units of meaning to the descriptive or inferential information compiled during a study. Codes usually are attached to 'chunks' of varying size words, phrases, sentences or whole paragraphs, connected or

> unconnected to a specific setting. They can take the form of a straightforward category label or a more complex one (e.g., metaphor). (Miles and Huberman, 1994, p. 56)

Miles and Huberman (1994) expand on how codes can be used to retrieve and organize data so that " the organizing part will entail some system for categorizing the various chunks, so the researcher can quickly find, pull out and cluster the segments relating to a particular research question, hypothesis, construct or theme" (1994, p. 57). Coding can be thought of as data simplification, indexing, or data reduction, organizing data to a manageable level (Coffey & Atkinson, 1996). The main goal in coding is to facilitate retrieval of data segments categorized.

Coding Process

Because coding is basically a data reduction method, the coding process does not necessarily result in meaning generation (Coffey & Atkinson, 1996). It is basically a "data reduction task" (p. 35) that creates categories and subcategories, or segments of data, that will eventually lead to some meaningful interpretations of the research data. As the title of this section suggests, it is only part of the process in data analysis.

It is important to note that codes and their segments can often become "nested" or "embedded" within one another, whereby segments overlap and intersect, sometimes resulting in more than one code per segment of data. Coffey and Atkinson (1996) state that "afterall, ordinary social action, including conversational talk, does not present itself to us in neatly bounded packages" (1994, p. 37). Thus, one can surmise, why should data from a conversational research interview be any different?

The coding process involves a series of reading and re-reading of research interviews in order to discover and establish the specific themes and appropriate codes inherent in the data (Coffey & Atkinson, 1996). The point is "...not to search for the right set of codes, but to recognize them for what they are: links between particular segments of data and the categories we want to use in order to conceptualize those segments" (1996, p. 45).

Interpretation

The coding of qualitative data allows the researcher "to recognize and re-contextualize data, allowing a fresh view of what is there" (Coffey & Atkinson, 1996, p. 45). As mentioned previously, coding involves the reading and re-reading of interview data, making selection of what to code and what not to code. This reading and re-reading process is considered part of the interpretative process. Decisions are already being made about what is relevant within the data set, which eventually becomes "the stuff" of meaning generation (1996).

What does one do once the data set has been " selected, cut up, fragmented, coded, and categorized" (Coffey & Atkinson, 1996, p. 46)? In other words, how does one make the transition from coding to interpretation? Wolcott (1994) describes the transition from coding to interpretations a "crucial one." He suggest that interpretation requires a going beyond, or transcendence of the "factual" data, and deliberate analysis of what is to be made of them (1994). Delamont (1992) posits that coded data must be interrogated and systematically explored for meaning generation.

The possibility of information loss in coding procedures is always of concern. A scrupulous and thorough coding procedure is typically the only safeguard against this occurrence (Coffey & Atkinson, 1996). Thus, researchers should always scrutinize their data sets for missing linkages or unidentified codes that didn't originally make the data set or established themes. One must move cautiously from the process of establishing codes to exploration of how codes and categories relate to the original data. One "...moves beyond the codes, categories, and data bits back to what the 'whole' picture is or may be" (1996, p. 46).

Miles and Huberman (1994) argue that data display is a key element in the interpretative or analytical process of research data. Codes and categories must be presented in an accessible and easy-to-read form to properly explore and generate meaningful data. The codes and categories are said to "make pathways through the data" (Coffey & Atkinson, 1996) and thus the significance of their presentation is obvious. Once a researcher has transformed coded data into meaningful units he or she wants to be alert for patterns, themes, regularities, or irregularities as well as contrast.

Generalizing, theorizing and generating meaning from the data involves both a descriptive and explorative process (Coffey & Atkinson, 1996). On one end of the spectrum one is attending to patterns and themes by way of counting phenomena, comparing and contrasting the data set. On the other end, one moves towards generalization, attending and questioning relationships between variables, looking for conceptual and theoretical consistencies within the data set.

To summarize the coding process it is important that coding does not necessarily occur before theorizing, but that the two co-occur. This elucidates a fact mentioned previously: "Analyses is always ongoing at every stage of the coding process" (Coffey & Atkinson, 1996, p. 47). In other words, coding does not occur in a vacuum and the

"...establishment of ordered relationships between codes and concepts is a significant starting point for reflection and for theory building from qualitative data" (1996, p. 48).

Steps of Analyses: Kvale

The purpose of the research interview is to gather qualitative descriptions of the "life world" experienced by research participants, with the goal of understanding, based on interpretation and meaning of the particular phenomenon under investigation (Kvale, 1996). Kvale's (1996) six steps of analysis are considered relevant to the specific coding procedure in the current study, and thus are briefly mentioned here: 1) Participant's descriptions of their lived world include descriptions of experiences, feelings, and explanations for their current conditions or situation; 2) Participants discovery of new meanings: discovery of new relationships and meaning during the interview may result in an awareness, or connection not previously known to participants; 3) Interpretations and condensation of interview content: interviewers interpret and condense content from the interview "sending meaning back" to interviewees; 4) Interpretation of transcribed interviews: interviewers interpret transcribed interviews; 5) Re-interview: interviews are conducted to communicate analyzed data from the interview as well as to give an opportunity for participants to respond and clarify interviewer's interpretations; and 6) Action, the continuum of description and interpretation inherent in qualitative research interviews may extend to include some form of action or change resulting from new insights or meaning derived from the interview experience (Kvale, 1996, pp. 189-190).

Interpretation of transcribed interviews listed (as step four of Kvale's (1996) six steps of analysis) is concerned with the specific methods of analysis used to analyze research interview data. This brings to mind the literature discussed by Coffey and Atkinson (1996) about the many different methods of analyses available to qualitative research interviews, as well as the importance of selecting the most appropriate and suitable method/methods for the particular phenomenon under study. Before discussing the specific coding method used to organize the data in this study, I outline four methods of analysis discussed by Kvale (1996) that are applicable to my work: 1) ad hoc meaning generation; 2) meaning condensation; 3) meaning categorization and 4) meaning categorization (pp. 192-204).

Ad hoc meaning generation does not champion any standard method in analyzing research interviews; rather it utilizes a combination of techniques pertinent to the topic and content derived from a particular study. An ad hoc meaning generation method of analyses is considered applicable to the current study because no one single method of analysis was sufficient for interpreting the research data. As stated above, three other methods were relevant to the analysis process. Because the purpose of this study was exploratory in nature (i.e., examining adolescents' experience of mental illness), many themes, meaning, and interpretations were generated.

Meaning condensation involved a condensing of the meanings verbalized by research participants into shorter statements (or formulations) that still held the central meaning or description of what was expressed. Essentially, this involved paraphrased statements of a few words that could later be transformed into categories, or themes of content. In short, meaning condensation involves a reduction of long interview text into shorter and more manageable statements (Kvale, 1996).

Meaning categorization can only occur with coded data, and thus was relevant to the current study. Various categories, or codes, were developed as a result of reading and re-reading the data content, which sometimes resulted in various subcategories. Kvale (1996) mentions that these “categories can be developed in advance, or arise ad hoc during the analysis” (p. 192). Because of the nature of the research interviews in the current study, categories and subcategories of data content emerged out of an ad hoc process. This involved reading and re-reading of data text, resulting in the creation and specification of various categorical themes.

Meaning interpretation goes beyond the manifest meanings in the data searching for “...deeper or more speculative interpretations of the text” (Kvale, 1996, p. 193). This method of analysis “recontextualizes” the data content or “statements within broader frames of reference,” leading to text expansion versus text reduction as seen with meaning condensation and meaning categorization. This is where the hermeneutic methodological framework is applicable to the current study attempting to establish deeper and richer meanings of the text data.

CHAPTER 4

METHODS

Participants

Three participants, one female and two males participated in the current study. Participants were between 18 and 34 years old. All participants gave informed consent. Participant criteria for the current study included: having had contact with an official mental health service; one or more diagnosable psychiatric illnesses; an outpatient or post-acute status; and absence of any active psychotic, suicidal, or acute depressive symptomatology. All these criteria were met, however two participants continued to exhibit some symptomatology during the research period. Participants completed a written demographic data sheet provided by the principal investigator requesting age, sex, and psychiatric diagnosis.

Recruiting Participants

All three participants were recruited through their psychiatrist at the request of the researcher. This occurred by contacting the psychiatrist within the Halifax region. Participant's treating psychiatrist, receiving a brief description of this study, was the first to make contact with them. The psychiatrist then contacted the principal investigator. A meeting was set up with each person to obtain informed consent and explain details of the study. The interview process began in the first interview for all participants. However, the initial interview did require more time than subsequent interviews because of the time required in introducing the study protocol. Participation was completely voluntary, giving participants the choice to withdraw from the study at any point in time without penalty. None of the participants withdrew from the study. Fictitious names were given to all three participants whom I will introduce in the data chapters.

Interviews: Protocol

A series of tape-recorded interviews, each scheduled for one and one and half-hours occurred for each participant in dialogue with the principal investigator. The interview process began in the summer of 1999 for participant number one, November 1999 for participant number two, and January 2000 for participant number three. All interviews were completed by February 2000. Each participant required a different number of interviews, with a range from four to ten interviews. The first participant required eight interviews. Participant number two completed his interviews in four meetings and participant number three required ten interviews. A professional transcriptionist recruited by the principal investigator transcribed each tape-recorded interview. Data from interviews amounted to approximately three hundred transcribed pages. Interviews were conducted in a formal mental health setting.

Structure of Interviews

A semi-structured in-depth interview style with open-ended guiding questions provided the data of the participants' mental illness experience. See appendix B for list of guiding questions. I will now describe Kvale's (1996) "semi-structured life world" as it pertains to the interview method applied in the study.

Kvale describes the "life world" as it pertains to phenomenological research and in-depth interviewing as "... the everyday lived world of the interviewee and his or her relation to it" (p. 30). This type of interview "...is defined as an interview whose purpose is to obtain descriptions of the life world of the interviewee with respect to interpreting the meaning of the described phenomena" (1996, p. 5-6). The purpose of the "life world" concept for the current study is to "describe and understand…[pivotal] themes [adolescents have] experienced and live toward" following diagnosis and treatment for a mental illness (p. 29). Information resulting from the themes discussed in the research interview between the interviewer and interviewee were analyzed with respect to the life world described by each interviewee.

Having defined the concept of the "life world," as it pertains to Schutz's phenomenology philosophy and Kvale's "semi-structured life world interview" framework, I believe this interview style was an appropriate method to investigate and learn about the lived experience of research participants. As a phenomenological researcher in the current study, what I sought to learn from my participants is summarized in the following passage:

> I want to understand the world from your point of view. I want to know what you know in the way you know it. I want to understand the meaning of your experience, to walk in your shoes, to feel things as you feel them, to explain things as you explain them. Will you become my teacher and help me understand? Spradley (cited in Kvale, 1996, p. 125).

The semi-structured life world interview structure method provided the opportunity for an in-depth look at the meaning and personal impact of a psychiatric illness suffered by the individuals who participated in this study. This method allowed participants to tell their stories and express their experiences as mental health consumers in an "open and unrestricted dialogue." Because this population never had such an opportunity (in a formal sense), I believe the in-depth semi-structured interview format helped to elicit disclosures relevant to the studied phenomenon.

CHAPTER 5

ANALYSES: CODING PROCEDURE

Reviewing Interviews

Once the interview process was completed for each participant, including the transcription of all taped-recorded interviews, I began the process of coding the data in preparation of analyses. Data was investigated using a manual procedure. A number of steps went into this process. The first step involved a line-for-line review of the information provided in the interviews, and had a two-fold purpose. First, a re-read of interview data was necessary following each interview to prepare for the subsequent interviews. This allowed for an opportunity to clarify previous interview data with the goal of ensuring accurate representation of participants' data. A general review of interviews, which occurred throughout the data collection stage of the study, prepared for the stage of identification and development of themes inherent in the data content.

Developing Themes

Step two of the coding procedure, theme development, began following review of the interview transcriptions. This was for the purpose of clarifying data content with study participants and obtaining general thematic content. This involved reading the interview transcription line by line and than documenting in the side margins, a short one-or-two word phrase describing what was said. The goal here was to identify and develop major themes discussed by each participant.

Once a number of topics or themes were identified, I organized these on separate cards headed by the topic or theme identified at the time. Data specific to each participant was summarized into short sentences giving a general description of what was said. Specific quotes from the original interview transcriptions were also included on these cards. To avoid confusing data between participants and to aid in a return to specific quotes within the original text, each card was organized to include the following information: participant's code name; date; interview number and the page numbers identifying the location of direct quotes to be included in the data.

Identifying Major Themes

Once a particular theme, or category, was established I began going through the interviews again documenting any occurrence of data related to the identified theme. Occurrence of data-related themes were presented for each participant so that each card started with data from participant number one and ended with data from participant number three. A number of major themes evolved from the interview data: 1) Experience with treatment and diagnoses; 2) Experience of symptoms; 3) Concept of mental illness; 4) Reflections of a mental illness; and 5) Reflections of the interview process. Within each of these major themes came subcategories of information forming subheadings for each major theme.

Modifying Themes: Final Data

The subheadings developed from the major themes came about when I tried to write up data of the major themes from the cue cards. I discovered that further coding was necessary because of the various subtopics within the major themes. This required a manual transfer of data from the cue cards to a notebook in the order it was organized on the cards. At this point I re-read all the data for each participant for each theme, documenting further themes in the margins of the text. This formed the final set of data to be presented in the thesis. Final presentation of data was written from this manual analysis.

Organization of Data Chapters

Participant's data is presented in separate chapters. This begins with a general introduction of participants' and their psychiatric diagnoses. This includes a general description of participant's personality features, a description of their diagnoses, and a personal account outlining the first stages of psychiatric symptoms to their contact with the mental health system. This is followed by descriptions of their experience of diagnosis and treatment of a mental illness presented by verbatim quotes intermixed with the writer's text. Each data chapter is organized into a number of topics including 1) Experience of a mental illness: diagnoses; 2) Symptom experience; 3) Experiences of treatment; 4) Concept of mental illness; 5) Reflections of a mental illness; and; 6) Insights and awareness. Each one of these topics includes a number of designated sub-themes identified by participants in describing their mental illness experience. Next, a chapter discussing the overall findings of the study with implications for counseling and future research is presented. Lastly, participants' reflective thoughts regarding the interview process are presented as the final chapter in this study.

Ethical Considerations

A first and foremost ethical consideration was the potential effects that the study might have on participants. A range of feelings including "...discomfort, anxiety, false hope, superficiality, guilt, self-doubt, and irresponsibility" (Van Manen, 1990, p. 162) are possible feelings participants could have experienced as a result of their participation in this study. Some potentially positive effects of the interview process include "...hope, increased awareness, moral stimulation, insight, a sense of liberation, a certain thoughtfulness, and so on" (p. 162).

In consideration of the stigma and emotional turmoil associated with a psychiatric illness, any of the negative effects of a research interview outlined by Van Manen were possible for the participants. Sensitivity and attention on part of the interviewer was required in order to guard against potential negative effects. Positive effects (outlined above by Van Manen) from participation in the study were equally possible.

Kvale (1996) discusses the differences between a research and therapeutic interview with respect to content and purpose (p. 24). Because sensitive information might emerge in a research interview, and thus sensitive reactions from participants, Kvale emphasizes the need for researchers who are conducting interviews to not engage in any therapeutic conversations. This is not to say that the researcher should not be sensitive to participant emotionality, but that the researchers not take on the role of a therapist while conducting a research interview. However, with respect to the interview process implemented in the current study, the interviewer was sometimes called upon to utilize her counseling skills because of the nature of the content and affective responses elicited from participants.

One last positive effect of phenomenological research mentioned by Van Manen is the potential "transformative effect on the researcher..." (1990, p. 163). Phenomenological research is believed to result in "deep learning, leading to a transformational consciousness, heightened perceptiveness, increased thoughtfulness and tact..." for both participants and researchers (p. 163). Kvale (1996) comments on the positive effects of phenomenological work, including research interviews specifically, and states that participants commonly experience interviews as "...genuinely enriching, having enjoyed talking freely with an attentive listener, and have sometimes obtained new insights into important themes of their life" (p. 128).

Ethics specific to interviewing as outlined by Kvale (1996) include issues of informed consent, confidentiality, consequences, and research and therapeutic interviews. Participants in the study were informed of the purpose of the study and the exact interview methodology to be utilized. This constitutes the "informed consent" required by participants both verbally and in written form. Another component of informed consent is the " briefing stage" (p. 153). This provides participants with the purpose and procedural instructions for the study. Opposite to this is "debriefing" which occurs immediately after participation in a study. The debriefing stage allows for additional questions or queries to be addressed by participants.

In conclusion, the research interviewer must protect participants' confidentiality rights including their specific identity and any potentially identifying information. Participant information gathered from the current study was not to be documented in the research text unless permitted by research participants. Also, and just as important to the issue of confidentiality, was adequate representation of participant information, especially if ever to be included in a published document. This was accomplished through a strict review of research data from the interviews, especially the direct quotes, with each participant.

CHAPTER 6: DATA

JOHN

John is a thirty-four year old male, married with a young two-year-old son. He participated in interviews from June 1999 to October 1999. During the interview period, John had to take a three-month break from the interviews because of a relapse in his illness, resulting in hospitalization. The possibility of a break in research interviews with John was communicated to me prior to his participation because of his stage of illness.

John described himself as a carefree, athletic and confident adolescent who was involved in many sports. However, he denied being a communicative person in terms of speaking of himself to others, especially in sharing personal information. He feels he is more of a private person, rejecting the company of large crowds in favour of solitude or the company of his wife and child. He described his need for privacy as a cocooning, or retreating, which he prefers, to socializing in large crowds.

John's experience with mental illness symptoms began early in childhood at the age of five or six years. Although not identified at the time, he was experiencing symptoms of Obsessive-Compulsive Disorder (OCD). This diagnostic disorder continued onward throughout adolescence and adulthood and remains present to this day. In fact, John did not communicate this problem to his psychiatrist until recently, so he has only begun to deal with struggles associated with this disorder.

Another form of mental illness John has struggled with, throughout his life, is depression. He believes this too, like his OCD, has been with him most of his life, further complicating his clinical picture. His first memory of depressive symptoms was in adolescence and early adulthood years. He began seeing a child and adolescent psychiatrist at fourteen or fifteen years old. He believes his illness occurred as a reaction to his drug and alcohol use, which had been a significant part of his adolescent and young adult life, until he married. He also believes the drug and alcohol use was a way he coped with his mental illness symptomatology, OCD and depression.

John did not see a psychiatrist between ages sixteen and twenty one, even though his OCD, depressive episodes, and drug and alcohol problems persisted. On experiencing his second major depressive episode during university, John once again came to the attention of a psychiatrist. Although he was prescribed medication and was formally receiving psychiatric treatment, he was not always compliant with treatment, and thus did not make much progress at this time. He denied any interest in giving up his drugs and alcohol, which he now believes was partly to blame for his lack of progress in treatment. He did not feel he was really connecting with the psychiatrists he was seeing, feeling like they talked at him, versus with him, further deterring his interest in complying with treatment.

John's final and significant experience with his mental illness came with a severe panic attack experienced over a year ago. This experience resulted in a visit to the emergency department of the local hospital. His panic symptoms were so severe that he actually experienced them as heart attack symptoms. This was subsequently treated with an anxiolytic medication called Lorazepam that acted to relieve his panic symptoms. Not surprisingly, John soon came to the attention of another psychiatrist.

Although panic was part of John's clinical picture at the time, it was soon realized he was in a major depression, requiring hospitalization on two separate occasions over the course of the past two years. His believes his current therapist, a female psychiatrist, has been the most helpful to him. Although he attributes his present gains in working through his mental illness issues to the good relationship between he and his psychiatrist, he believes his motivation to get well is much greater now than it has ever been in the past. In resuming interviews with John, following his last hospitalization and a three-month break from research interviews, he presented and admitted to be feeling a lot better in terms of his OCD and depressive symptoms. Although John admits and realizes he still has further to go in terms of complete recovery from his illnesses, he is confident that things will only get better.

The Experience of a Mental Illness

Diagnostic Label

Upon receiving a psychiatric diagnosis, John recalls struggling with symptoms of Obsessive Compulsive Disorder (OCD) and depression early on in life, although he never received the ODC diagnoses until more recently. Although he was quite aware of his depressive symptomatology during adolescence and young adulthood, he did not pay much heed to diagnostic labels, which was evident in his lack of compliance and commitment to psychiatric treatment. The acceptance or non-acceptance of a diagnostic psychiatric label or mental illness was not really an issue for John even though he himself admits that he was troubled in his youth. Only upon reflection of his experience with diagnostic labels was John able to communicate his mix of feelings towards this experience:

> *I have become much more comfortable with the labels...the label itself and even the disease itself that has been going on through my life, you know, I look at it now as more of a something that needs to be corrected rather than just something*

> *that is running my life. It's, you know, it's, I don't have quite the same negative feeling that I did have about it and I feel in control now.*

John denies any resentment problems with the psychiatric labels, stating that:

> *It never bothered me really I don't think at any point. I like having the diagnosis...having myself diagnosed that way is almost a relief because I know what I am dealing with... maybe not day-to-day knowing what I am dealing with but an overall picture. I know what it's like and what it can do to you and that I am very afraid of it. I don't like it going on in my body and what have you, but at the same time, I know what it is about. At least I know it is not something else. I am mentally ill you know, I can say it. Sometimes it sounds strange to me but it doesn't really have a negative connotation to me. It's the negative connotations that other people may put on me--hearing the word is what I am more afraid of. I have come to the sort of point where I don't care too much either.*

In asking John if he had the choice to have or not have the label, he expressed a mix of feelings. On the one hand, he fears that without the diagnostic labels he may not have received the help he needed to deal with the disturbing symptoms he has experienced in his life, and thus might be in worse mental shape than he is now. Also, he believes that the labels and professional involvement of psychiatrists aided in relieving him of certain responsibilities when he was acutely ill with depression, as in leave from work responsibilities. On the other hand are the stigmatizing effects of being judged and denied certain privileges because of having a mental illness; however, John feels this is lessening, as expressed in the following quote:

> *I think it comes down to people's interpretation...about the negative connotation of the term (mental illness) and I think it is changing, having the term mental illness, people don't necessarily think quite as negatively as they once did...I think more because of the media or through the health profession, it served up the message that a lot of people are suffering from mental illness and a lot of people are suffering from depression in our society now...those numbers seem to be going up as well for whatever reason, so, it is something that more people are aware of... I think or you know, people who want to know about it more are more aware.*

Stigma

John's concern with issues of stigmatization of a mental illness was more prominent in his youth, particularly in his childhood years. In reference to his OCD symptoms he was very concerned and afraid what others would think of him should they discover his OCD habits. Some of this concern and fear originated from his own ignorance and lack of insight of OCD. It only makes sense that he would fear reactions from others when he himself did not understand his OCD symptoms. He speaks to this in the following quote:

> *As a child, I knew I wanted help, I wanted it (i.e., OCD) to stop, but at the same time I didn't want people to think that I was, you know, having problems and I didn't' want to accept that I was having these problems.*

In adolescence, when John engaged in heavy drug and alcohol use, he recalls wondering if others thought that he was crazy. In fact, he was convinced that others believed this to be true of him. This bothered him at times, but not enough to deter him from his alcohol and drug-related behaviours. Nonetheless, he did not like to talk about or share his mental illness for fear of being judged by others.

More recently, although John is still somewhat protective of his psychiatric diagnosis, fearing the negative connotations still attached to the term mental illness, he is now less concerned about others' potential negative reactions, and feels that getting better is the most important thing to him now.

Fears

Fears related to John's mental illness included his OCD symptoms, panic disorder symptoms, and crowded environments. Although his experience of depression and panic attacks were quite unpleasant and debilitating, his OCD symptoms were the first set of mental illness symptoms that caused personal distress in terms of fears and concerns. Because John developed OCD at the young age of five or six years old he was unable to understand or articulate these symptoms and subsequently left to his own accord in coping and making sense of this experience. His first reaction was to internalize his OCD, interpreting it a flaw or defect of his person:

> *Obsessive Compulsive Disorder I have had since as long as I can remember, and I never knew what it was. I thought there was something wrong with me and I was afraid to talk about it...I don't think that I probably talked about it much until I started to see DR. X [recently]. I know it has been a problem for a very long time, but now she tells me that it's not just me, that- you know, that I thought there was something in myself that was doing it or that I had something wrong with me.*

John goes on to express his frustration, embarrassment and internalization about his OCD symptoms stating:

> *As long as I can remember that being a very, very frustrating part, I could never explain it to anyone else really. I don't know if I was embarrassed by it or, I guess I was embarrassed by parts of it and other parts, I just thought that I was, I don't know, crazy or there was something wrong with me or something wrong with my brain. I remember thinking that as a younger kid.*

John's reluctance in talking about his OCD experience as a child was motivated by his concern that some unknown negative outcome would result. However, because of the intensity of his OCD he often engaged in habits around others that could potentially reveal the illness. For example, he spoke of school experiences, whereby he would have to count words before he spoke when called upon by the teacher, or when he felt compelled to ask kids to say certain words before he did, or to stand in a certain spot or place for a fixed amount of time. All the while the kids having no idea or clue to his request. John described this as a scary experience:

> *That was almost like the scariest part when I did things like that, like looking back on it because that was letting it out and people I know, thinking, O.K. this guy has got some problems and you know, why is he doing this-- and me thinking these people are going to tell other people. You know, something is going to happen.*

Panic attacks became part of John's mental illness experience in adulthood. One particular distressing attack came during a staff meeting at his workplace. John believes a number of factors could have precipitated this event, including the number of people in the room at the time and the experience of heart-attack-like symptoms earlier that morning. Apparently John was also seeing a number of medical professionals prior to this panic attack for investigation of physical symptoms that concerned him. However, no medical condition was ever diagnosed. John shares his thoughts and feelings at the time:

> *Feeling pains in my chest again and was concerned about other illnesses, like maybe having possible heart problems or something…and when I had an episode-because of hyperventilation and what have you, all of my arms and legs went numb and so I became quite fearful something was happening. And I didn't want to go to the hospital at first, but after that started I was thinking, 'am I having a stroke or having a problem with my heart?'*

Although John's experience with panic attacks or panic disorder was not prominent until adulthood, he believes that the anxiety provoked by large crowds today was probably present in adolescence; however it may have been obscured by a combination of adolescence itself along with his use of alcohol and drugs. In speaking about his experience in crowds in relation to his alcohol and drug use John states:

> *I have always been a bit uncomfortable to some extent…I just didn't like being in crowds. When I did, say, go to a concert or something like that, I always had alcohol and drugs to help me along…I would use the drugs and alcohol in those sort of circumstances to, I guess, help me get through whatever I was dealing with.*

Coping with anxiety and panic-like symptoms today poses a challenge for John, particularly those episodes precipitated by crowded environments. Although he can sometimes walk into a shopping mall (for example) and cope quite well, other times he has great difficulty:

> *Almost panic-stricken about the other people, especially if it's a busy day and most of the people are around me. And I am not always fearful of the people, I'm afraid that something is going to happen, I'm not afraid something is going to happen to me, but something overcomes me and I get very anxious and have difficulty functioning, and something about the amount of people...you feel like 'get me out of here' that sort of thing.*

When John is having these types of episodes he states: " *I can develop quite an agoraphobia over that time and I think I mentioned before, I am still not one for crowds.*" As mentioned before, John prefers his own company and that of his wife and child.

John not only experienced panic attacks and the fear associated with that among strangers or co-workers, but he also had panic attacks near family as well. For example, he spoke about an incident at Christmas time whereby he had to have his father take him away from a family gathering because it was causing too much distress. His feeling about this was:

> *My father had to take me out of the house a couple of times when those (large social gatherings) sort of things were going on. I just couldn't handle them for some reason. It is scary in some ways because they [family] were so close. And even the other day...we were at my sister's and her husband's place and we were just outside and I had a mild panic attack even than just the people that were around me. There were some others, you know, my brother in-law's family was there as well as a few extra people. It was surprising to me that I would have a panic attack in that setting, in that situation but it does still happen.*

In asking John what he makes of having panic attacks around family members, he states: "*I am not sure, it scares me a little.*" John expressed concerns about his readiness to return to work in the fall because of relapse experiences with his illness. In discussing this he states:

> *Because I want to return to school and teaching in September, and you know, I feel most days that I am doing fairly well. But when I have setbacks, especially if they are on the moderate side of things, it concerns me a little bit because I want to make sure I am clean before I go back basically:*

John was unable to return to work in the fall but made December his next goal, expressing similar concerns and fears about potential relapses:

> *I hope to go back for December, that's what we're [doctor and I] working towards. I don't know at this stage if I'm going to be or not. I've had some relapses, and that's why we tried different medications. Sometimes when I started feeling pretty good and things are going along, and then the first thing I know, I basically crashed, and that's very scary*

Symptom Experience

John recalls experiencing a lot of frustration with his OCD attributing this to both his ignorance of the disorder and his inability to articulate his pain with OCD. Consequently, he never got the help he needed in those early years when his OCD was at its worse, creating another source of frustration for him. He talks about the frustration he experienced in relation to how his mother reacted to his OCD, albeit unknown to her at the time:

> *I don't even know how to explain it because we (mother and John) still don't talk about it really. I mean I try to explain to my mother a little bit. You know, she use to make fun a little bit of little things that she could see-- the physical things that I did like having to line up my shoes, or slippers you know, in a certain way, or having to put things on a table a certain way. She used to say those things and now I say to Mom, you know, that was part of this whole thing and that wasn't fun for me, it was you know, very difficult having to do that sort of thing. So now she understands a little bit more.*

Although John denies projection of any blame towards his mother for not knowing or understanding what was happening to him, he still cannot forget the intense frustration he experienced in not being understood, not just by his mother, but by others as well:

> *I am a little leery of saying too much about it. I say a little more to my father and maybe to a lesser extent to my mother now...I try to explain it to my wife a little bit and she can understand, but she doesn't always know what I am going through. I don't think she understands how difficult it is for me. How much it takes out of me and how exhausting it really is.*

John also experienced frustration in not being able to better control, limit or prevent the development of both new and old OCD habits. For example, when I asked him if some of his OCD habits would die out and be replaced by new ones, he replied:

> *Yeah, and some would be the same but with a twist you know. Instead of having to say something out loud, I would do it in my head, or things that I would have to do physically, I could picture myself doing them and that would take the place of doing them physically, that sort of thing. It was always very frustrating. I guess,*

> *you know, it is still evolving. It is something that you know, it has ruled my life and more than I would like to think about.*

As an adolescent, there were times when John would get so frustrated and fed up with his OCD he would just try and stop whatever it was he was doing. This would sometimes work and sometimes not. He states, "*...I would get so frustrated...I 'd just try and stop it and it was extremely difficult to do that...it would be hell days really where I would just go through and I would just try and not do that.*"

In reference to John's depressive symptomatology and the treatments associated with that, he lost his recall memory function for quite some time, which created intense frustration for him. When asked if this was frustrating for him, he stated:

> *Very frustrating. Being a teacher, and I guess it was just part of my personality that I like to read, I think about things, and when I went to university I was interested in courses involving an awful lot and that sort of thing...it was very frustrating not being able to recall when this last episode hit.*

John makes further comments regarding the frustrations of a depressive illness:

> *When you're in deep depression, really nothing else matters, nothing, sometimes when you are in such a deep depression that you just don't care about anything. It is very, it is not very nice feeling anywise and ah, it is difficult when you look back on it saying how can you think like that all the time, and you know, it is very frustrating...having feeling of sort of uselessness and just emptiness that won't go away, that pervade through your whole being that's very frustrating.*

Some of John's OCD habits included having to cross lines and walking on sidewalks, washing and straightening things a lot, and having to place things in a certain way. On top of causing frustration, John's OCD compulsions acted to interfere with his concentration and ability to do things because he was so preoccupied with his obsessions and compulsions.

John's earliest memory with his OCD is described in the following passage:

> *I remember, the earliest I remember having a very difficult time with it. I would have been five or six years old. We took a trip to Montreal and there was a lot of bad things that happened then for me. I don't think that a lot of people knew what was going on. I think it was out of environment and things like that as well. I had a lot of difficulty on that trip and as a young child I remember that I was quite upset but didn't voice those things to my parents or anybody else at the time.*

John sometimes described his OCD in this way:

> *I sort of looked at it almost being possessed at times. Having something in me that was doing it to me as a younger child because I didn't understand it could be done with chemicals and still not probably fully understood by people."*

Other compulsion John exercised as part of his OCD included having others say or do certain things. For example, when in junior high school he would have other students say certain phrases because he could not for whatever reason. He speaks to this stating:

> *When somebody used to say, I'm jinxed, that word you know, and you are not supposed to say anything for some time. I wouldn't say anything and if I was called upon by the teacher to where I would actually have to talk or something, I would count each word that I said and then I would have to have somebody say my name each time for each of those words. So I would try and get somebody to*

> *say my name x amount of times or whatever...usually with kids I knew, I wouldn't be, you know, bullying them but I would be making them stay there and say, they wouldn't have a clue what was going on of course. That was almost like the scariest part when I did things like that, like looking back on it because that was letting it out and people I know, think, okay, this guy has got some problems you know.*

Another OCD habit or compulsion of John was constant checking:

> *I am a checker too. I have sort of calmed down a little bit. The stove was another thing I was checking. I would check the stove a hundred times over the course of a day just seeing, especially if we were going out on a trip or something*

John also talked about how mentally exhausting his OCD could be because of having to go over and over things in his head leaving little space for concentrating on other things. He described this stating, "*mentally exhausting, because it is always there. Something that you're always doing, you know it is like having a conversation with yourself all day.*"

In relaying this experience John recalls a specific example that well describes the process, amount of detail and time consumption involved in the compulsions associated with OCD:

> *I remember when I was a kid at school...they had a fairly large pavement thing with lines on it for the ball fields and that sort of thing. There was probably six or seven places where, or maybe not even that, but counting little cracks and things. I probably would count the corners of buildings and stuff, there were six, seven or*

> *eight places that I would have cross over in a certain way and if I didn't cross over in that way, I would have to go back and cross.*

John feels his compulsions have definitely changed over time and although he is better able to conceal them these days, they are just as troublesome as they were in his youth:

> *I think it was more difficult when I was younger but the compulsions and obsessions have changed and I don't like them the way they are now. I didn't like them the way they were then, but I think because of age that I was not understanding it. It was very difficult for me as a child. I don't like them now either but I can deal with them a bit more efficiently sometimes. Some other times I still get very frustrated.*

John talked about his ability in blocking out some of his OCD from both the past and the present:

> *Yeah, I am still blocking it out. I don't want to think about it because I am always trying to erase or coverup or not have things initiated. Like even if I sit here talking to you, there may be things that you know, that I want to do, and I just don't. Other things that I can't do that with.*

John spoke about his helplessness in controlling his OCD and the frustrations in communicating his symptoms so others would understand:

> *It is not like something too that if you explain something to somebody like in a text book and they go, oh, I get it now. Unless you have gone through it, I don't think people could actually understand what you are talking about. If I said to somebody, why did you go back and cross over that line with your left foot while*

> *you were was swinging your arms in a certain way you know, I did that 45 times, people would go, what? You know, they might know it is obsessive compulsive.*

John describes the difficulty in having to manage his OCD with his other responsibilities:

> *It is almost like you have to have a dual role, two parts of your mind going at the same time or two things going at the same time because you're always thinking about these OCD things, requirements and different aspects of the OCD. You know, the organization is one thing but you know, the rituals and ah, other aspects, but at the same time trying to do what you are supposed to be doing in the normal course of whatever, you know, it just happens to be education of children. And ah, I had a real conflict there sometimes because it's difficult to push this OCD aside and you know concentrate on other things that need to be spent time concentrating on. It ruled my life basically when I was a child, and right up, it still is a very strong part of my... you know...who I am. It doesn't show itself physically, unless you really look for it, I guess. It used to, but now more of it is in my head, and things like counting and saying things in my head, I do it more, but it's non-visible.*

Depression

John has suffered about three major depressive episodes, the first occurring in adolescence, the second in his early twenties, and the most recent this year. Although he feels he has suffered other depressive episodes in between, they were not as acute as the three major episodes.

Initially, John spoke about the difficulty in explaining his depression, especially to others:

> *To tell you the truth, I can know that feeling, I can know the time and I can see the pictures but I can feel the same way, the same mood (when not in a depression). I tried to explain this to my wife the other day that I know what it is like and I know these is nothing worse that I have ever had to deal with but at the same time I don't know how to explain it really, it's just, you know, lack of emotion and lack of feeling, lack of energy. It's just, you know, any of that part that's you is being sucked up.*

In addition to John's expressed frustrations with depression found on page 53, he adds further comments on this issue: "*But, ah, when you are in it (depression), when you are in that hole, you have a different perspective. Your thoughts don't work properly.*"

John's experience of feeling like he is in a hole during an acute depressive episode was so strong at times that he felt it overshadowed his OCD stating:

> *When I get very depressed I think that maybe some of the OCD falls away because you know, I get in such a hole that you know, nothing is going to overtake that depression and just my ability to do anything, you know, is very strong.*

John talked about how his depression altered his thought processes and how one has to come out of it before one can relate to other things or see things differently. He spoke of it as a place you don't want to be and how much one wants to be helped out of that place, yet, how difficult this can be:

> *You really have to come out if it (i.e., depression) before you can relate to other things ...you know when you are depressed but you don't want to be, you don't want to, you want people to help you get out of there. At the same time, you are*

> *having these feelings of, sort of, uselessness and just emptiness that won't go away – that pervade through your whole being -- that's very frustrating.*

John felt that his depression altered his perception so much that he had to have his mood stabilized to some extent before he could even begin to deal with the OCD. This was because of the negative thought patterns associated with a depressive episode that can hinder any type of mental progress. John felt that if he didn't get his mood under control, he would not have the desire or energy to work on his OCD. He felt he wouldn't even care since that is a common feeling associated with depression. Now with an improvement in his mood, John states, "*that is why things have worked out well, I think that having the mood under control with the medication and counselling has helped with the OCD.*"

Another problem associated with John's mental illness symptoms worthy of mention was his use of drugs and alcohol. Although he does not necessarily attribute a causative role to these substances in the development of his mental illnesses, he definitely feels his depression was exacerbated or complicated by it. Nonetheless, at the time, he felt that it helped him to deal with certain circumstances, particularly his angst and panic in social situations. John states: "*I would use the drugs and alcohol in those sorts of circumstances to, I guess, help me get through whatever I was dealing with.*" Although he admits to his preference for drugs and alcohol during his youth to cope with his mental condition, he now has a different perspective on this:

> *When I was having a more major episode of depression during my university years, ah... doing a lot of drinking...because I was depressed, I was looking for something to help get me out of it. Now, the drinking isn't going to do that, it*

> *changes things for awhile, it changes thoughts processes and what have you, but really, in the long run, it is more of, ah, you know, it's a depressant itself. So it's not going to help bring you out.*

Panic

Panic attacks, a form of mental illness, are a more recent experience for John. His panic attacks, particularly his first major attack in the past year at his workplace, coincided with depressive symptoms that developed into another major depressive episode. Prior to this attack, he recalls not feeling well physically or mentally, and experiencing a lot of physical symptoms:

> *That summer I was having a lot of problems with the way I was feeling physically, the way I was feeling mentally, but I didn't see it as being, sort of a clinical depression that was coming up. I was having a feeling of my heart beating, and these signs are sort of things that happen with panic disorder, but because I hadn't had that component before as deeply associated with the depressive episodes, I didn't know what was going on.*

Because John had no experience with a real panic attack in the past, he didn't quite understand the physical symptoms he was experiencing. He describes the development of his panic disorder:

> *I became quite concerned about my health, I started having some more mild panic attacks and than I had an attack for the first time that was a little bit on the more moderate side to strong side of things. I felt like I was having a heart attack. My chest was tight. I was having problems with my breathing, I was very disoriented, sweating--all those sort of classic symptoms."*

With respect to some of John's more mild attacks, he described a lot of anxiety, stating, "*also, I was having very anxious feelings, like to the point where I would have to go and get up and walk, almost to get out of the way, the tensions out of my way.*"

Prior to John's first big panic attack he had been experiencing a lot of unusual symptoms; numbness on the right side of his body, sleep disturbance, and breathing difficulties. Because of this, he had visited a neurologist to allay his fears; however it wasn't long before he experienced a major panic attack resulting in a visit to the emergency department of the local hospital:

> *I had an episode of hyperventilation, and what have you, all my arms and legs went numb and so I became quite fearful that something was happening. And I didn't want to go to the hospital at first, but after that started I was thinking: 'Am I having a stroke, or having a problem with my heart?', So, I said okay...take me to the hospital.*

This attack occurred at work during a staff meeting, and John was relieved that he had not been teaching in the classroom at the time:

> *Luckily I wasn't actually teaching a class. It was at lunchtime that it happened, and I think the kids were out for that afternoon, that was probably why we were having a lunchtime meeting, so, I am grateful it didn't happen when I was teaching. But, yeah, it was quite disturbing.*

Experience of Treatment

Therapeutic Relations: Psychiatrist

Overall, John did not have a problem receiving treatment from psychiatrists. However, he did have different attitudes about this between the time he was first treated in adolescence and his current treatment as an adult. In total, three different psychiatrists have been involved in his treatment. The first was a child and adolescent psychiatrist (male) during John's mid teens; the second, another male psychiatrist during his late teens to his early twenties, and the third, a female psychiatrist who is his current therapist.

John described his treatment experience with his first psychiatrist as somewhat comfortable and relaxed stating, "*I remember with Dr. X, I remember being somewhat comfortable with him. I remember that he smoked cigarettes, and allowed me to smoke at the beginning... but that stopped after a while...but I remember feeling relaxed with him.*" He described treatment as more talk therapy–oriented: "*like I said I wasn't taking any meds at the time, and it was more talking.*" Overall, he felt that the treatment helped him get back on track mentally and physically, but questioned how helpful the therapy sessions were at the time since he was not then 100% willing to accept help:

> *So sometimes I would go in with an attitude, other times if I wasn't having a good day I remember I would sort of sit there and he would talk, and I was more, I'd feel, like he was talking at me. Now that probably wasn't the case, but it was just that things were exploding towards me because I had said something about something in relationship with whatever, and then after awhile I would just sort of shut off, and that also repeated itself somewhat while I was with Dr. Y when I had depression around age twenty-one or twenty-two.*

John said more to say about his feeling of not being helped as much as he wanted, or expected in treatment with his first two psychiatrists. He attributes part of this to his own resistance and part to his feeling of being talked at:

> *I remember having some level of boredom at times because, them (psychiatrist) trying to explain to me what was going on, and because of my age or just because of, you know, level of depression or whatever, I was in, at that time, I really wasn't too interested in having people, you know, talking to me, or at me at the time. I really wanted to spend more time conversing with them rather than just saying something, well, you know, this is what I did and them have me talking for the next half hour about why it is that I probably did that.*

Although John denies the quality of relationship with his first two psychiatrists, he did admit to having fairly good rapport with his second psychiatrist even though he wasn't ready to accept treatment. He states, *"I went to the sessions that were usually once a week or so, and I liked Dr. X as a psychiatrist, you know, I got along with him and had a fairly good rapport with him, But I don't think that he always understood where I was coming from."* John recalls one memorable experience with this particular psychiatrist that left him feeling not only misunderstood, but also quite angry and betrayed. This came about in the sharing of some of his personal journal writings with his psychiatrist and his mother's discovery and sharing of his writings, which were not intended for others:

> *Dr. X asked to see some of these things and I had showed him some of these things and at one time he asked if I was writing this for him and I was really insulted in a way...I wasn't doing that at all, they were all very much for me...I think it was something that even my mother found that concerned her and he thought I had written and left it somewhere for her to find, you know, to be concerned. That wasn't what happened at all. I remember feeling very, I don't*

> *know, almost betrayed or something...feeling frustrated, you know, to tell this person that that is actually not what happened, and feeling that he was feeling that I was not telling the truth.*

John had shared his journal writings with his second psychiatrist and his first doctor as well. Overall, he expressed disappointment in the responses to, and interpretations of, his journal writings by both psychiatrists. He felt they had over interpreted, or read more into the writings than was actually there. He experienced both anger and frustration in the intimations made by his first psychiatrist that his writings were meant as a cry for help, rather than for himself:

> *With Dr. X I don't remember having the anger there with him. I was being more, wishing more things would happen, but I wasn't angry with him. He didn't do something with that information to make me feel bad, but I was angry with Dr. X after that episode, absolutely, yeah.*

John described his treatment by a psychiatrist during his teens as somewhat tedious, but attributes this more to the nuances of adolescence than to the psychiatrist. He states, "*but at my stage, at my age, I found them, and it could have been anyone I suppose, I found it sometimes tedious, and as I say, it probably was somewhat to do with my age and somewhat to do with my illness.*"

John describes quite a different treatment experience with his current female psychiatrist compared to his experience with male psychiatrists. He states:

> *Dr. Z being a woman is, I find a different experience. She is a different personality, but she works from a different position, and being a woman, and may have different mannerism, or different whatever, and still be very professional.*

> *It's, I don't know, I can't probably hit the nail on the head about what it is, but there is a difference there for sure, just in the way things are presented.*

In comparing his relationship with his current female psychiatrist as compared to the male psychiatrists, he states:

> *Now I know with Dr. Z it is very different, since we have a good relationship, and I listen as carefully as I can to what she is saying, and she just doesn't talk and talk and talk and that sort of thing. She really is very good at what she does. I am not saying that Dr. X and Dr. Y are not good at what they do, because they are, but at my stage or age, I found it sometimes tedious and, as I say, it probably was somewhat to do with my age and somewhat to do with the illness itself.*

In treatment with his current psychiatrist, John believes he has made a lot of headway: "*So I now feel that we have a fairly good handle on things, and you know I would like to say that we've turned the corner, but I'm a little bit hesitant to do that. I hope that it's at the end rather than the middle.*"

Treatment

John first received medication therapy in treatment with his second psychiatrist for the depressive symptoms he was experiencing in his late teens to early twenties. Because he was using a lot of alcohol and illicit drugs at the time, medicating himself in a way, he did not stick with the medications he was prescribed:

> *I did start meds then, and there was only one medication- I think it was...and that was the brand name or whatever, I'm not sure what the drug was. I'm pretty sure it was... and because of the alcohol abuse and the other things I was into at the time I really wasn't interested in being cured or having my problems addressed*

> *really…I sort of took the medication when I felt like it, which I see now needed to be taken on a fairly regular basis, and I didn't care.*

John was reluctant to take his medication because of such side effects as decreased libido:

> *I think it affected my sexual ability somewhat, being you know…being at the age twenty-one or whatever. That was a big deal for me, so I didn't take the medication on schedule. I didn't take it very often. I ended up throwing it out most of the time just to make it look like I was taking it. But I was taking medication for the first time for something at the time, but I wasn't taking it properly as it was being prescribed.*

One significant but unpleasant experience John had with some of the medications was memory disturbance. He found the medication made things a little "blurry or fogged." This included memory problems with things like dates, times of appointments, or details of conversation he recently had with someone. This resulted in great frustration for him most of the time. Nonetheless, he expressed a positive side to the memory lapses he experienced describing this as somewhat of a liberating experience. The loss of memory was a respite from the negative feelings and emotions he experienced as part of his mental illness. In speaking to the positive effect of both the medication therapy and the Electro Convulsive Therapy (ECT) he received as treatment, John states:

> *I think that the medication along with the ECT, um, helped as well to sort of, um, level the playing fields so to speak. It sort of erased some of the more negative memories that I have had, recent memories that I had and, um, sort of left a blank slate in some ways with the mind.*

Overall, John believes the treatment modalities (i.e., medications and ECT) he received more recently were positive and have helped him significantly. In speaking to the progress he has made with treatment he states, "*I think that has to do with the medication, you know, as well as my will to try and get rid of some of the symptoms.*" John's experience with medication therapy extends to his experience in hospital. This is discussed in further detail in the following section: hospital experience.

Hospital Experience

John experienced two hospitalizations over the past three years with the most recent one in the past year. He uses a comparison format at times in communicating his experiences between the two hospitals. In speaking to his hospitalization experience, he discusses his relationships with both the treatment team (i.e., psychiatrists and psychiatric nurses) and the in-patients he came to know during this time. He also shares some general comments about the environment itself as it related to his psychiatric experience.

In a general way, John experienced his in-patient psychiatric admissions as more negative than positive stating, "*since I have been hospitalized twice, ah, the experience, ah, for me personally has been more negative than positive.*" Nonetheless, John was quick to add that he probably needed the hospitalizations at the time, or at least in the case of his first hospitalization, and was typically satisfied with the treatment he received:

> *I know it sounds a bit of a contradiction in terms, but...at the same time, the professionals, the health professionals, around me, the nurses, and the doctors, and mostly the nurses made me feel quite comfortable... I don't think I encountered either in the [first hospital] or here [at this hospital], one nurse that*

> *you know, I didn't find to be doing their job and going beyond that and just being nice and you know.*

When it came to nursing care, John usually had positive experiences, feeling that the nurses were always there to help, or explain things regarding his treatment. In speaking to this he states, "*the nurses I found were very good about explaining things they could and the reasons for doing things, and you know, why you should be doing this at certain times or what have you.*"

One frustration John did experience in relation to nursing staff during his second hospitalization was the fact that the nurses did not have the authority to discharge him. He experienced this feeling about two weeks prior to his formal discharge near the completion of his ECT treatments:

> *I remember the last couple treatments and, ah, knowing that I was feeling better, but also felt that I could be sort of doing what I was doing at home as easily. But the doctors at the time weren't as available and it happened to be that the doctor and psychiatrist on the floor at the time actually went away for four or five days or something like that. So I found it very frustrating because I wasn't allowed to be discharged by the nursing staff.*

In addition to his psychiatrist's unavailability and not being discharged when he requested, John also experienced frustration about a mix-up in his medications because the doctors were away. John experienced a mix of frustration, irritation and anxiety regarding this experience, which he communicated to his family:

> *I think I was communicating my frustrations to my parents and to my wife about still being an in-patient and some of the things that were going on at that time.*

> *Like the psychiatrist being away and some other things that were happening with meds and you know, was told some things were going to happen with my meds that didn't transpire, went a different route. There were just a couple things that sort of happened to snowball my anxiety.*

Although John experienced some frustration with the nurse's lack of power to discharge him home, he did not blame the nurses or hold them responsible for this:

> *There wasn't a lot that they could do about getting me released you know...but because I hadn't finished my treatments I would still be kept in the hospital, so, in that way I think they were saying, probably ready to go but they probably, you know, bit their tongues a bit because they don't want to be going against, saying things against what is actually happening.*

John felt that the last two weeks of his admission were unnecessary and served no benefit:

> *I don't think that there was a real benefit to it, ah, that I was staying there now. I know there may have been some, you know, in an underlying way, but, ah, I think that I could have convalesce just as easily in my own home as I could have in hospital, especially since I was sharing a room with another person which is very difficult and was causing me a great deal of anxiety which is something that I was trying to deal with as well, you know, reducing the anxiety.*

One other frustration John experienced in relation to nursing care was an encounter with one particular nurse during his first hospitalization experience. He often experienced poor memory function during this admission resulting from a combination of his illness and the medications he received. Because of this he often found it difficult to remember things like dates, times and other things related to his treatment, like what medications he was taking:

> *But there was one day that I knew a nurse--not a nurse assigned to me at the time, but a nurse that I had had a lot of contact with-- and she asked me about my meds, and it was a day that I was just not in a good frame of recall. And you know, I went through what I was taking, but I was getting very confused and she said, 'you should know your meds.' And I remembered that at the time that she was saying that, and that frustrated me a little bit, you know, because I was thinking, you know, she should know this, I'm trying very hard to know, but I mean I know that everybody gets a little frustrated, and I think it was at a time when people were thinking maybe that I was getting a little better than I actually was, so maybe that played a little bit of a part as well too. I'm not sure, I don't know.*

Although John admits to having better relations with some psychiatrists than others during his hospital experience, he generally experienced them as knowledgeable and helpful in a way. However, he denied ever feeling really listened to by the psychiatrists, stating, "*I think of the patients that they do see...under their care...they don't seem to be listening quite as intently and it's really looking at it more as a problem to be solved, sometimes in a medicinal way.*" He suspected this was due to the high volume of patients each psychiatrist saw.

When John compares his experience with the nurses to the psychiatrist, he did not feel that the doctors put as much effort and time into explaining things about his treatment. He believed they were more concerned with treating overt symptoms than underlying problems. He speaks to this experience stating:

> *Sometimes they (psychiatrist) may say I'm doing this, or we are going to try this, and not tell you why or their thought processes behind, or why they changed their mind about this, or that, or why start this drug at this time, or that sort of thing. Instead of looking beyond that sometimes, for the other problems, or the underlying problems, they really treat the overt symptoms. They are not wanting to talk so much as a therapist but more as a physician, just to try and eke out the, you know, problems with mood or feelings, or what have you.*

John felt that the psychiatrists in the hospital functioned more on a business level, similar to how a family medicine doctor would function in treating physical symptomatology: "*I think because of the volume of patients that they see, they are keeping it on more of a business level like it would be if you went into a private practitioner and you had a cold.*" Basically, John felt that they approached illness from a symptoms perspective versus exploring psychosocial issues or underlying personal issues that may be part of a patient's presentation.

Typically, John experienced more of a delay in receiving information about his treatment from the psychiatrist than from the nursing staff stating, "*just sometimes, they took longer than, ah, others depending on what type of questions were asked and what kind of concerns and that sort of thing.*"

His experience with psychiatrists in the hospital was that they were not so concerned with underlying psychological issues as they were with overt surface issues to be remedied typically by medications. He did not feel that the psychiatrists were interested in looking at other avenues of treatment, and preferred to rely on traditional forms of treatment:

> *But what can happen I guess is that they get into a routine about...if they start treating, ah, people with similar illnesses, like I say, depression, with similar drugs all the time. They are not looking for other avenues of, or maybe more appropriate avenues of trying to treat the problem.*

Although John experienced many frustrations with his hospital experience (of which I will say more about later), he also experienced the hospital as somewhat liberating in terms of not having to worry or fret over other responsibilities: "*It came to be liberating, as I say, because when I got into the culture of the institution in which I was with other people, and that sort of thing, the time didn't really seem to matter that much.*"

He experienced the environment itself as having its own culture, describing it as a micro-community similar to normal society but with people that are messed up a bit:

> *So, it is like normal society except that you have this micro community and people are a little more messed up if you want to use that term. Sometimes the extremes are a little bit larger than they would be, ah, in a normal society.*

One problem John did have with the environment was the lack of privacy. This was during his second admission at a psychiatric hospital that was different from his first psychiatric hospitalization. His experience in having to share a room with another patient was:

> *Well, it is also, you know, when people have visitors, ah, you know, you sometimes feel like you want to give them their privacy, you know, all you have is*

> *the curtain there, that you know, there are other times that they may be in when you want to sleep or you, you know, you want to be having some time in the room and ah, or just, you know, want to be by yourself, and you can't do that you know, it is difficult.*

In contrast to John's lack of privacy during his second hospitalization, he did have his own room in a different hospital, which made a big difference for him. In speaking to this, he states:

> *I had my own room, which made a big difference between there and the [second hospital]. Whereas at the [first hospital] I was sharing a room with another person and I am very, sort of, ah, private person when it comes to that sort of thing.*

Another frustration John experienced with the hospital environment was the unit rules controlling times he could come and go. This was especially true with his second hospitalization since he did not feel the need for this admission as much as he did with his first admission.

In terms of relationships, or attitude towards co-patients, John believed relationship building was quite important and significant to his hospital experience. He denied getting too close, or personal, with everyone; however he definitely feels he benefited from some of the relationships, or interaction he had with other patients: "*I developed some good relationships with some of those people, some in a more casual way, others in a more, I guess stronger relationship.*" John believed patients acted as a support to one another stating, "*I think, you know, it is part of the experience you need,* *that sometimes, you need to be able to talk to the people because some of those people are going through the same things that you are."*

Even if a patient was not having the same experience as John, or someone else in the hospital, he still thought they benefited because of the support offered in listening to each other:

> *Some of them are going through different things, and you know, it works sort of a two way street. That you can talk to them, and they can talk to you, so they have someone to talk to, and you have someone to talk to, and people to listen to concerns and that sort of thing.*

John felt that he and his co-patients were able to share information about various treatments, or hospital procedures they had been through, in a way that was helpful to one another. This provided one another with details that might not be provided by the treatment staff: "*they can, you know, tell you in a little more detail about what is going on, or what is going to happen, or what was their experience anyway."*

Although John mostly found the hospital environment interesting, he also experienced it as depressing at times:

> *In the hospitals themselves, I found to be, ah, both at the same time depressing and at other times, or at the same time, very interesting places to be sometimes. It depended on the day-to-day sort of mood and ah, different way that I was personally feeling and different contacts that I had with people that were in the hospital with me at the time.*

He spoke of times with both hospitalizations in which he really wanted to leave, questioning the hospital about the necessity of his continued admission. This somewhat depended on his mood and perceived need for hospitalization at the time:

> *Both places became a time when I sort of, because of the tedium of the sort of day where you don't have the responsibilities, I was anxious to leave the place where I was. This sort of depended on my mood and how well I understood my necessity to be where I was to determine the, sort of, the degree of wanting to leave.*

Despite John's desire to leave the hospitals at various points of his admission, he definitely believed that his first hospital admission was much more of a necessity than his second admission. He described feeling more patient-like, believing he was really sick and needed to be in hospital to get the proper help:

> *When I was at the [first hospital], I felt that I was more sick, or pretty sick, in a depressive state. It was just a different sort of feeling, in a holistic way and more that I was a patient at a mental hospital, a mental, you know, some sort of institution and, ah, there was a real need for me to be there...ah, and it was a necessity that I be there even though I didn't always want to be there, but I felt that I was sort of on the same level that a lot of the patients that were there.*

In summarizing his hospital experience, he states:

> *In a general way, yes, I feel satisfied that things were done for me which helped my condition. There were things along the way that I wasn't necessarily happy with, or didn't maybe agree with at the time. I think if I compare the experiences between the [first hospital] and [the second], I would have to say that it was more positive at [the first], but I think that that has a lot to do with the relationships*

> *that I did make. It was a bit of a different setting, ah, I was there, I think I was more needing to be there. I guess in my own mind anyway, more ill.*

However, John feelings about his second hospital admission were different:

> *When I was at [there], ah, especially as I neared the end of the ECT treatments, and I was spending a lot of time in the hospital just sort of letting the day go by, I felt that I didn't need to be there and, ah, in fact, there were days where I was just sort of saying, just discharge me. I can get out of here, I can handle things now, and ah, I needed to start the next stage but that wasn't happening so...I knew I had some problems and, ah, I needed some help, but I didn't always feel that I needed to be an in-patient to receive the help.*

Concept of Mental Illness

In speaking about a mental illness, John denied having a problem with the label itself, yet he avoided using the term "mental illness" in conversation with others, stating: "*I usually don't use the words mental illness, I usually talk about being depressed or something like that.*"

John very much believes that the trials and tribulations associated with the developmental stage of adolescence definitely impacted on what later became labeled a mental illness. He denies adolescence as being the sole culprit in the development of his psychiatric symptoms, however he feels some of the depression and drug and alcohol use was very much connected with that period in his life:

> *Part of it was adolescence and part of it was just not caring, you know, and going through some of those other things. There was certain times with the OCD when I was sort of smashed into adolescence at the same time. It just got messy and I got*

> *angry and mixed a little alcohol and dope in to the whole combination and just you know, things got kind of wild-- I think I was a little bit off.*

John believes that a chemical imbalance, in combination with environmental stresses, very much influences the development and perpetuation of a mental illness. This is congruent with the medical model's theory of mental illness, attributing the development of psychiatric symptoms like depression, panic disorder, and OCD to chemical imbalances in the brain that require psychopharmaceutial interventions. In speaking to this issue, John states:

> *Well, I think that obviously that it has shown that chemical imbalances have a lot to do with some types if mental illnesses and depression especially...I think there are external factors that help to, ah, either bring on the illness, or once it has started, or the precursors are there with the chemicals, there are other external factors that help to bring things along. From my experience, I can think more vividly about when I was sick, ah, as an adolescent and, ah, I know that it had to do with the chemicals in my head that were imbalanced. But I was also going through a stage that everybody goes through as they grow up and it made things difficult with relationships with family and friends to some extent as well.*

In summarizing his concept of mental illness, John expresses comfort with the mental illness label viewing it as something that needs correcting rather than something he is doomed with for life:

> *I'd just say as a finishing sort of thing that I have become more comfortable with the labels...the label itself and even the disease that has been going on through my life, you know, I look at it now as more of a something that needs to be*

> *corrected rather than just something that is running my life. It's, you know, I don't have quite the same negative feelings that I did have about it and I feel more in control now.*

Reflections: Mental Illness

Self Concept and Perceptions

John's illness has been with him so long that he experiences great difficulty in removing it from his self-concept even though he is presently working towards this goal. He feels it is difficult to imagine aspects of his life without some reminder of his illness. Up to the point of his latest recovery with depression he really doesn't remember a lot of good times in between his struggles with OCD and depressive episodes:

> *Most recently, it (mental illness) was, you know, a thing that I just couldn't get away from, something I am thinking about now, I started to be able to remove myself a little bit, I have some techniques that I have been given to try and relax myself a little bit more and not think always about the disease.*

He often wonders if he might have been a different person had it not been for the OCD and depression symptoms in childhood, adolescence, and adulthood. He states that the OCD has been such a big aspect of his life that it is tough to see how things might have been without it. He talks about the difficulty in knowing what life would have been like without the OCD because growing up with OCD is all he knows, and thus can only surmise how things might have been for him had he not developed it. Although he feels his experience with OCD and depression has resulted in more personal strength and has shaped the person he is today; he believes that the negatives outweigh the positives. He has often asked himself what he was doing, feeling that he has wasted part of his life; and consequently he feels very frustrated that he wasn't helped earlier.

In terms of John's desire and necessity to be rid of his OCD and depressive symptoms, he speaks of himself as going through a "metamorphosis." He attributes this to psychiatric treatment in the form of medications and Electro-Convulsive Therapy (ECT). He experienced this as a positive step toward separating himself from the presence of his mental illness symptoms.

John spoke of his experience with drugs and alcohol as a teenager and how much this has molded his persona, both professionally and personally. In thinking about his experience with drugs and alcohol, he often wonders if he might have become a different person had he not indulged in drug and alcohol use in his early years:

> *It (i.e., the drug and alcohol use) was fairly intense and it was a part of my life for a number of years and I look back on those years, and wonder sometimes if I hadn't done those things that I had done I would have been a much different person...it was something I became known for. It was part of my persona. It was not something that I wanted to give up at all.*

Nonetheless, John admits to liking this experience at the time and had little motivation to quit his habits regardless of the personal consequences. He feels there is no getting away from the impact of his illness on his personality today:

> *In a general way, it's sort of defined, ah, my being in a way since I was young. I have had a label, or have had the experiences of having the depression and, ah, obsessive compulsive disorder, ah, and it's something that has followed me...But, those labels and those experiences tend to follow me in a personal way and in a*

> *social way. The people that I know and the way that I think has been molded somewhat by the experiences that I have had with the mental health system and with my own sort of trials with my illness itself. It has definitely had an effect of the way that I think and the way that I act.*

Although John's experience with drugs, alcohol and mental illness played a major role in his personality development, he believes that abstinence from drugs and alcohol has given him a better handle on things that were once clouded by the use of psychoactive substances.

Losses and Frustrations

John experienced a professional loss in that he had to resign his teaching responsibilities for an extended period of time because of the acuteness of his illness:

> *It's been very difficult in that way, you know, being a professional, and I feel like I've been letting my staff and the children in my class down, that sort of thing. I know they're in good hands, and I have come from a very small school with a very small staff who are very supportive and I consider to be good friends of mine... I have moments of guilt and want to be able to be involved more, but I know that I can't and this is the best way now with someone in the classroom doing what they are doing with the children. I can't do it so someone else is.*

John had concerns about his peers perceiving his work as substandard as his illness progressed. He believed his performance as a teacher was below his capability, which in effect severed as a "*breaking point*" for him to attend to his mental illness difficulties.

Reflecting back on this time, John admits to a number of losses and frustrations including poor attention and concentration, memory loss, sick time from work, missed appointments, mood changes, and poor hygiene. Overall, he was most frustrated with a decrease in mental capacity whereby he could not fulfill his professional responsibilities:

> *Very frustrating, being a teacher, I guess it was part of my personality I like to read, I think about things...and I like to think of myself as a fairly bright individual at most times, but not being able to have that function... it sometimes becomes very very frustrating.*

Another loss that had a huge impact on John's personal life was his inability to qualify for mortgage insurance because of his illness. His most pressing concern with this was the fact that his wife would have the burden of the cost of their home should he die. He expressed great frustration with this wondering how this might carry on into other things as he and his family proceeds through life. His overall feeling about the impact of his mental illness label is expressed in the following passage:

> *I know that sometimes the label can follow you through the course of your life, but, ah, hopefully after a certain period of time, you know within five years, or ten years, that you haven't had this problem, then maybe they are willing to wipe the slate clean so to speak. It is a bit like a bad credit card, and there is not a lot you can do about it. It's, you know, once it's there, it is on the record.*

Memory loss was another source of frustration for John. At the height of his illness, both prior to and while in hospital, he often was unable to keep track of dates, or who visited him from one day to the next. In fact, his concentration and attention for things was affected dating back to early childhood when his obsessive-compulsive disorder was at its worst. He felt that his mental preoccupations interfered with his ability to do things because he was thinking about other things, resulting in extreme frustration. This experience of frustration was expressed in an earlier quote found at the top of page forty-eight.

Not being able to control his symptoms of OCD, John often suffered silently, fearing the occurrence and disclosure of his habits should someone find him out. He had a sense of something being wrong with him because of his OCD. He was not able to understand or communicate this to anyone for fear of being judged, or something-terrible happening, as a result of self- disclosure. When he reflects upon this period of time, he does so with great frustration, regret, and sorrow at having to go through the OCD experience. Furthermore, he expressed concern at anyone else ever having to go through the same thing:

> *I look back now that I am a little older and see yourself when I was younger. I feel sorry for myself--because I wouldn't want any child to go through what I had gone through as far as the OCD goes, because I know it was extremely frustrating for me and, ah, you know, I wouldn't wish that upon my worst enemy.*

He often expresses great frustration in allowing his OCD to go on for so long without asking for help, and not receiving the help he needed from professionals. Nonetheless, he acknowledged that he is partly responsible since he could not communicate his problems to anyone. He feels he has wasted, or lost a lot of life because of the OCD, often asking what it was that he was doing. However, he was unable to stop, or do anything about his illness symptoms, fearing the possible consequences of being discovered. John admitted to often trying to hide his OCD habits by making up stories as to why he was doing this, or that behavior, so he didn't have to tell what was really going on with him.

John also experienced great frustration with some family members and others in that he didn't feel they really understood his mental illness. He felt there was a lot of misinterpretation, causing him increased frustration in coping with his own experience. Although he acknowledges all this now, he informed me that others noticed changes in him before he did. Subsequently, this resulted in further frustration for him because others were always asking him if he was alright when he himself thought he was fine. He didn't realize he was regressing in his illness, and thus was unable to appreciate others' concern for him.

Stigmatization related to John's OCD was a source of great frustration and embarrassment. He was quite guarded about his OCD, constantly worrying about what others might think fearing they might get the wrong ideas. Even when he came to the attention of a psychiatrist as an adolescent and young adult, he still did not disclose his OCD. Only recently has he been able to deal with his OCD in treatment with his current psychiatrist.

John experienced the feeling of being regarded and spoken to differently because of his mental illness experience. He felt that neither he, nor others, would know quite what to say to each other, making for some very awkward moments. Although he describes some of these moments as subtle, he still felt others were judging him, or perceiving him as being messed up:

> *Well, with the label, some people you know, immediately get a bit, sort of wondering you know, mental illness, well, that doesn't sound good at all. Should my daughter be seeing this boy? Is this a good friend for this person to have?*

In asking John if he believed people were actually saying and thinking such things of him, or was his mind just working overtime, he replied: "*I think it was a little of both. I don't have any direct proof that people were, you know, saying 'don't play with John because he is messed up.' Indirectly, I felt that was going on a little bit.*"

His perception that others regarded him as a little messed up left him feeling not very good because he didn't feel that it was his fault. He felt that he couldn't do anything about the depression or OCD.

John admits to going through a wild time for a few years prior to high school. He attributes this partly to adolescence, and partly to "just not caring" because of the difficulties he was going through at the time. He felt that there was a time with the OCD when he sort of "smashed" into adolescence, making things very messy, leaving him feeling very angry a lot of the time, resulting in increased use of drugs and alcohol to deal with his emotional distress.

Irrespective of the stigma John has experienced in response to his mental illness label, he now feels a sense of relief that his OCD has been diagnosed and is finally being treated. Because of this he is not too concerned with what others think, feeling the most important thing to him is to just feel better.

Relationships and Isolation

John had much to say about the impact of his mental illness on his relationships. Since his mental illness experience dates back to early childhood and continued onward into adulthood, the impact of this on relationships has been significant. As a child when his OCD first began, he denies any significant relationship problems in terms of conflicts with anyone. However, he did feel isolated and distressed by his OCD symptoms since he was unable to articulate, or talk about his experience. Later in life he experienced some anger toward others, family, and professionals, at not being able to help him with his OCD. Nonetheless, he acknowledged that his inability to ask for help was in part responsible for the lack of support given by others.

As an adolescent, John experienced great relational difficulties with his mother. This was often over his drug and alcohol use that he now acknowledges as a coping mechanism for his OCD and depressive symptoms. He feels that his relationship with his mother was more strained than his relationship with his father. John attributes this to his father's busy work schedule as a physician, thus limiting his availability at home leaving the disciplinary role to his mother. In reflecting upon his relationship with his mother during his tumultuous teens, at which time he used a lot of drugs and alcohol, John states:

> *I was pretty rough to get along with family wise and would do some things that were not the most healthy things to do to myself...I was not violent, but definitely had some hostility, especially towards mother... well I was taking it out on my mother to some extent...I felt that she was interfering with the way things should be playing out in my life...I didn't feel I was being given enough latitude to work within at the time.*

Upon entering university John reports a decrease in his hostile feelings and poor relations with his mother, but it hasn't been until recently that they have begun to discuss his past. More recently, he has examined the impact of his illness on his marriage relationship. He speaks of the responsibility his wife has had to assume because of his mental illness experience.

> *She had to deal with a lot of things besides her normal work load and what have you when I was incapacitated really, for a couple of months she took on the role... she did all the calling and setting up of what ever needed to be set up and basically became the person that took care of everything rather than us sharing. She had to deal with all those sorts of things...she did very well, but it was a stressful time for her.*

John has struggled in talking about his mental illness with his wife. In asking about this possible obstacle in vocalizing his internal experience with mental illness symptoms he states:

> *Yeah, I think that is part of it [not being understood]. It is not like something too if you explain something to somebody like in a textbook and they go, oh, I get it now. Unless you have gone through it, I don't think people could actually understand what you are talking about.*

In light of what both John and his wife have had to contend with, he believes they have done well as a family.

John's relationship with his one-year-old son became very significant in light of his mental illness. Although he denies any adverse effects of his illness on this relationship, his son was just a year old when he was at the lowest point of his illness. Although experiencing great happiness with visits from his son (and others), this caused him great anguish since he was unable to feel and respond to his son in the ways he wanted.

John expressed concern about his son picking up his OCD habits: "*I think about him a lot, and you know, about my compulsions and that sort of thing and how they are* *interfering with my relationship with him.*" Cognizant of the literature on learning models of behavior, and the genetic vulnerability for transmitting mental illness within families, John often worries that his son may already have the "precursors" to OCD. For this reason, he works very hard at curbing his OCD habits in the presence of his son, however difficult this may be at times.

On the positive side, John reports that the birth and presence of his son is a major motivating factor in resolving his mental illness symptoms, so that his son is not affected by his condition. He talks about the love he feels for his son and the positive relationship he has with him:

> *I love him more than anything, he is just the greatest thing and because I have been off work for awhile I have been able to spend more time with him...I am able to look after him and we have a good relationship and my wife and I spend as much time as we can with him obviously.*

Even when John has some difficult days with his depression or OCD, he is still able to interact and play with his son.

John had a strong experience of isolation resulting from his mental illness. His first experience with feeling cut off from others was at the age of five or six years old when his OCD habits first begun. Reference to this experience is found on the top of page fifty-two where John describes his earliest memory of OCD. John had a lot of concerns in voicing his OCD symptoms because of his ignorance of what was happening to him, and fear that if he spoke about it, something even worse might happen. This left him feeling very alone and isolated from others.

As John's depressive symptoms progressed in adolescence, he reports further isolation. He spoke of being very much a loner. He felt he was his own best company comforting himself with activities such as journal writing, poetry, reflective thinking, and drugs and alcohol. He became most uncomfortable in social crowds, often avoiding them altogether. He attributes this to his illness and an introverted personality that prefers solitude and socializing within small circles of close family and friends.

Insights and Awareness

In talking about his relief in receiving his OCD diagnoses, John expressed an insightful awareness of the impact of a mental illness, particularly on his life:

> *I know what I am dealing with...I know what it's like and what it can do to you and I am--I don't like it going on in my body and what have you, but at the same time, I know what it is about. At least I know it is not something else.*

John believes his mental illness has had such a significant influence on his persona that it basically ruled his life for a long time:

> *I always knew it was a big part of my life you know, that it was really ruling my life. Thinking back on it now, I can sort of look at it over the time period and see how things have evolved where I couldn't do that so much when I was younger because it was just less time you know...I look back, and sometimes I guess I feel sorry for myself in away. I feel sorry that a child at that age had to go through some of the things that I did...I just wouldn't want to wish that on any child of that age because, you know, it just didn't do my childhood any good.*

Prior to John's first serious panic attack, he very much believed that a lot of his physical symptoms (breathing difficulties, dizzy spells, racing heart, numbness and tingly) were related to some medical condition such as a bad heart or something of the sort. It wasn't until his first major panic attack resulting in a visit to the hospital emergency that he finally realized that it was his mental state rather than his medical state that was the problem. In speaking to the connection between his panic like symptoms and the development of panic disorder he states:

> *It did become a little more acute at school and I guess this is where most people were saying things and my wife was also saying, you know, are you alright just because of the changes in my mood obviously she was seeing as well. I started having-- sort of dizzy spells, or disassociated sort of spells and became concerned about that as well...anyway, it culminated when basically I had those first panic attack sessions and came to realize and put the pieces together.*

When John reflects on the impact of his drug and alcohol use on his mental state, particularly in his adolescent years, he now realizes how it both delayed and sabotaged any attempts in having his psychiatric issues treated.

> *I think I would be afraid and have been cautioned fairly severely about taking alcohol or other drugs (illegal) while taking these medications and what have you. I would be afraid to do that...I want to get better...I feel pretty much like I felt-- not very good for basically my whole life and I am not going to mess that up by reverting to some of things that I used to do...I have sort of weaned myself from that sort of thing.*

John also realized the negative impact of his drug and alcohol use on his personal relationships as well as his psychiatric treatment, stating:

> *I just started feeling bad all the time, or feeling worse and worse and didn't want to be that way, and of course when I got married five years ago and, you know, I was with my wife for a couple of years before that. Obviously you can't stay in a healthy relationship with that going on.*

In asking him to consider the difference in his awareness of his mental illness issues between his adolescence years and his current experience in relation to his drug and alcohol use he states:

> *I feel like now I have a better handle on what is going on. Not that I can do anything about it, but I do feel more in tuned (as you say) with what is going on with my body and not blurred by the alcohol and drugs and what have you.*

John feels his abstinence from drugs and alcohol has heightened his body awareness, allowing him not to confuse mental and physical reactions secondary to his internal state versus reactions secondary to alcohol and drug use:

> *I can tell when something is going on mentally, or physically in my body because it is going on, it is not being done because of, you know, taking this or taking that or what ever and also some of the drugs like caffeine and what have you, I have been warned off which I have reactions to as well.*

In response to his awareness of the impact of his alcohol and drug use on his mental health, John adopted a positive change in both his behaviour, and attitude toward substance abuse and the management of his mental health, respectively.

> *I started eliminating all those things from the list of things that I know that if something is happening and there is something going on--I am, you know, chances are it is the beginning of an anxiety attack, or I had better get that*

> *checked out...I am told to watch for warning signs for certain things, and I am still like, like I mentioned, still concerned about my health to some extent because of what I did to my body that number of years.*

During one of his hospitalizations in being treating for a major depressive episode he relayed an interesting experience of a co-patient that spoke very deeply to his experience of his mental illness, particularly his OCD. This patient he speaks of was thought to have obsessive-compulsive traits indicative of OCD, which is one of John's psychiatric diagnoses:

> *When I was in hospital there was a fellow that was probably around middle aged. He had very systematic ritualized things about brushing his teeth and you know, how he ran the water and how he, you know, put the toothbrush on the counter...and he would be very slow and methodical and I felt you know, 'your messed up'. I wouldn't say that to him obviously, but I was thinking it... but I realized that I do the same things just in a different way. It is not as overtly you know.*

John went on to say that although he too still has his own obsessions and compulsions, his increased awareness of how his illness is expressed and the impact it has had on his life has definitely resulted in better control and management of his symptoms:

> *I think that because of the medication and because partly I have a one year old boy, and partly because I am just extremely frustrated with the whole thing, some have been more controlled is the word, but I have eliminated, or tried to eliminate some of those classic ones I have had, or tried to think about not doing them.*

To elaborate on John's awareness of both the desire and need to change he described himself as going through something of a metamorphosis in himself. He attributes this to a combination of factors.

> *My desire to want to change, and you know, really get control of some of the OCD things...or the necessity and just sort of finally saying, you know, enough is enough. I can't, you know, go on like this and operate in the normal way in the social, emotional and professional basis--you know, so--but there has been a metamorphosis in myself over the past number of months. I think that the medication along with the Electro Convulsion Therapy (ECT), um, helped as well to sort of, um, level the playing files so to speak. It sort of greased some of the more negative memories that I have had, recent memories that I had um, sort of left a blank slate in some ways with the mind.*

Although he believed his own internal resources, the need to change and desire to change, were essential in his recovery: the input of his psychiatrist, psychologist, and treatment plan (i.e., medication and ECT) were just as significant.

John expressed a number of things he has learned in his experience of living with a mental illness:

> *I guess I have learned different things in different ways about the illness in a personal way. I've learned more about the depression itself...the dynamics of how it works and that sort of thing as well. Um, and about the medications and how they work and don't work...as well on different facets of the disease, but, um, in a general way, I have learned a lot of things about myself because going through this over the past number of years. Things about, I am trying to think of*

> *the word, about limitations and, ah, that sort of thing about social relationships and about, ah, various different things I guess. I'm having a hard time making this.*

In talking further about this experience John summarizes his insights as a result of his mental illness experience:

> *The whole thing I guess is sort of brought together with the experience I have had with the health care system, and with the personal experience with the disease itself. I have, you know, come to understand more about the disease of depression and more about OCD. It has helped to make things a bit clearer in my mind how to work with myself and try, and, ah, make things better especially with the obsessive compulsive. The depression is more of a medicinal thing in harmony I guess with the exercise and that sort of thing.*

Although he has expressed great insights in what he has learned about himself and his experience of a mental illness, he is nonetheless just as aware of the work ahead in reaching full recovery:

> *Life is a little bit difficult trying to get rid of some of these things. It's a new experience, but it's, ah, like you say, it's like 'leaving an old friend', because it hasn't been very friendly at times, but it's, at other times, its nice to have the relief of you know, finally tackling some of these things that I have been struggling with, but, ah, at the same time, it is difficult letting go.*

In asking John how this new experience is for him, he states:

> *It feels good for the most part, it sort of chimes in well with, ah, you know, around the time of the birth of my new son, you know, I was sort of sick at the time but I*

> *was making some decisions that I wanted to get the OCD, and the depression of course as well, you know, under control and, ah, I really wanted to make some progress with the OCD because I didn't want it to have an impact on my son's life and our relationship. It was just the beginning of his life. So, it's really been a new beginning sort of for both of us.*

Reactions: Others

In reference to John's OCD symptoms that began in early childhood, he recalls his parents not really being that aware of what was going on with him. There were occasions where they would question a particular behavior, but he felt this was more out of curiosity than serious concern. He recalls his mother making fun of some of his OCD behavior, unaware that it was part of a mental illness. His description of this is included as part of a quote found at the top of page fifty-two.

In terms of the role John's mother played in response to his illness and problems associated with that he states: "*My mother was involved in an outside way, but sometimes she was caught up with the problem rather than the solution- let me put it that way, I don't know the exact thing, but she was less willing to accept the fact that I was having problems.*"

John attributes some of this to the fact that his mother fulfilled the disciplinarian role more than his father, stating:

> *Because he worked long hours at the job that he did, he wasn't as available to the children sometimes as much as he wanted to be, but when crisis situations like that came up he was more available, and he definitely took over that sort of role when needed.*

Although John's father was not as available to him during his youth he still felt he was supportive and a good role model for both him and his siblings. It was his father who connected him to psychiatry when his mental illness problems began in his youth. He spoke of his father as: "*a very fair man, and a good role model for myself and my siblings, and perhaps that is why some of them followed in the medical field as well... My father always came to my aid in that respect and has been very concerned- I mean for all his children, he is a very understanding and gentle man.*"

Now that John is an adult he feels his wife has somewhat replaced the role of his parents in terms of who is most involved with his illness. This sometimes carries over even to his treatment plan with his current psychiatrist. He states:

> *Now it is my wife, and sometimes our one year old son has come to the appointments--not every appointment- but sometimes- and that will help sometimes because she (wife) wants to be involved and see what is happening, and she sometimes can shed light on what has been going on at home better than I can, or from a different perspective.*

John felt that others usually noticed his illness symptoms long before he did. This was particularly true with his depressive symptomatology.

> *When I get into those stages I don't really want to ...its' usually other people that make the diagnosis for myself...other people saw me slipping into this depression long before I realized myself that I was getting as far into it as I was...There were little episodes and little things, people were always asking me if I was feeling alright and that sort of thing, and I was thinking 'I wonder why she bothered*

> *saying that' because I would feel alright, and you know, that sort of thing. Obviously people saw that my mood was changing.*

John recalls his wife and co-workers noticing changes in his mood and general well-being often asking him if he felt all right. His response was to usually brush this off, often wondering why people were expressing concern. Initially, he thought he must look a little run down. He still did not buy into the fact that he was headed for a major depressive episode until he landed in hospital.

When John experienced his second major depressive episode, others noticed changes not just in his mood, but changes in his memory and general ability to function. He was forgetting about scheduled appointments, both work and non-work related, and was neglectful of his personal grooming/hygiene practice. He feels his poor memory function worsened just before his hospitalization:

> *I was having more and difficulty with recalling events and dates and things that happened. And that seemed to continue to spiral downward as far as having that ability to recall, and came to sort of an apex when I was in hospital.*

John believed his memory problems were partly due to his illness, and partly to his medication treatment. He recalls this being a source of frustration for his family and people in general:

> *There was a couple times when people had come in and I wasn't sure if they had actually been there, or had been there a day before, or a week before... I know it was frustrating to other people. It indicated to other people that I was having problems when I would say- you know, like, well you have this test on Wednesday, and I wouldn't know if it was Tuesday, or Monday, or what day of the week it*

> *was, so that was sometimes frustrating to them because they would have to tell me several times.*

In an overall way, John feels people in his life, extending from family and friends to co-workers, were very supportive. There were times when some extended family members were leery to ask him directly about his illness in fear of stirring things up. John recalls some people questioning his ability at the time to properly care for his own child, or whether he should be alone with his son during his bouts with depression. However, aside from occasional concerns, he experienced a lot of support from all those personally involved with him.

CHAPTER 7: DATA

PETER

Peter is a twenty-two year old male who lives at home with his parents and holds two jobs while attending university. Although Peter reported having many friends and being involved in many sports, he also admitted to being prone to pessimism, often worrying and fretting about things that would not be of concern to others. He also felt that he was a bit insecure, suffering from low self-esteem throughout his life. He told me that he was the type of person who always wanted to help others, and often did help his high school friends. He said that his mother once commented about the many female friends that would call to cry on his shoulder and request his support. At the time Peter experienced his mental health difficulties, he said, "*I always wanted to help others, I was now asking myself, what about me? Now I need help.* "

Peter's first experience with psychiatric symptoms came when he had a severe panic attack while vacationing in Florida. His symptoms at the time included breathing difficulties, perspiration, a racing heart and an unexplainable sense of fear. While shopping at a sporting goods store, Peter witnessed a news report on a TV, which showed a car race in Toronto where an accident had killed a crowd member. At this time, Peter's father was in Toronto, and he suddenly panicked thinking that the person killed in the stands of the racecar crash was his father. He immediately made contact with home. His mother reassured him that his father was nowhere near the crash and was completely safe. Peter reports that his panic symptoms subsided shortly after speaking with his mother, and he had no further episodes during the remainder of his trip, or for two months until his next panic attack.

Peter's next experience with panic disorder symptoms occurred within the first few months of starting university. While sitting in a classroom he suddenly experienced the same symptoms he did in Florida along with some tearfulness. He fled the classroom, escaping to the restroom, and subsequently telephoning his mother for support and reassurance that he was okay.

Peter's panic attacks continued a number of times over the course of the next two-to-three months. His parents finally convinced him, despite his reluctance, to see his family doctor. Although he did not feel like his usual self, and noticed changes in himself including: low mood; decreased motivation; and social isolation, he resented others' concern about him, often pushing people away not wanting to face that he was unwell.

Peter originally thought that his doctor would just give [him] a "smack in the head", figuratively speaking, of course, telling him to come on and get with it. To his surprise, while visiting with his doctor, he realized things were much worse than he had imagined. His doctor diagnosed him as having panic disorder and depression that would require medication and the attention of a psychiatrist. His doctor referred him to a psychiatrist, and agreed to see him on a weekly basis for supportive counseling until the psychiatrist was available.

During Peter's first visit to his psychiatrist he was informed immediately about his diagnoses of depression and panic disorder, and was prescribed an antidepressant medication to treat his psychiatric symptoms. This initial treatment lasted for over one year. Peter said he was included in the decision-making regarding his treatment (i.e., the medication therapy) and time needed with his psychiatrist.

Peter informed me that he continued on medication for sometime after he began to feel better, and slowly decreased his medication and treatment sessions with the psychiatrist as he made progress. He was on medication for a year or so, and continued therapy for about the same period of time. When interviewed, he had been off medication and had not required the service of his psychiatrist for over a year. At the end of the interview process, and to this day, Peter continues to do well.

The Experience of a Mental Illness

Diagnostic Label

Initially, Peter had quite a negative reaction to seeing a psychiatrist, not to mention receiving a psychiatric label to describe his experience with sad moods and panic symptoms. His first reaction in visiting a psychiatrist was: " *I thought I was...this is rock bottom. I'm off to a psychiatrist, and they send crazy people to a psychiatrist.*" Peter felt the stigmatizing effects immediately, envisioning the stereotypical things one would about seeing a psychiatrist. He states:

> *The couch, you know, him (psychiatrist) sitting in the chair with a pad and glasses, the clock on the mantel, just expecting all those things. And that's not what happened. There was paper everywhere and....more like a business office.*

Peter was diagnosed immediately with depression and panic disorder, and reacted to this diagnosis:

> *Depression...almost felt worst...based from what you see on TV and media. Originally, I didn't think of myself as depressed-- family doctor didn't really say that directly-- just asked if I felt sad--feel he was warming me up for the psychiatrist.*

Although Peter still has a bit of an aversion to the term "mental illness", he now feels it was probably necessary in order to get the proper treatment. He admits to feeling comfortable enough with the idea of a mental illness and receiving professional help. He agreed that he would seek this out should he ever become mentally ill in the future. Lastly, he communicated a comfort in recommending others to a psychiatrist, without reservation, should they ever become ill with a mental illness. He states, "*my attitude now about mental health professional--no stigma, that is what they are there for-- trained to do what they do...I would tell people to go for help-- that's what they (psychiatrist) are there for.*

Stigma

Peter was initially horrified by having to visit a psychiatrist and even worse by the assignment of a "mental illness label." Not only did he question his own mental stability, wondering if in fact he was crazy, but he also became very preoccupied with reactions from others regarding his illness. In response to asking him if he was concerned about others' perception of him in having a mental illness, he states: "*That's right, what other people would think. Everyone has seen psychiatrist and the people in hospitals (mental), like, "One Flew Over the Cuckoo's Nest."*"

Eventually, Peter felt more comfortable about sharing his mental illness concerns with a professional. However, he very much feared judgement from his peers or non-professional individuals: "*I feared friends judging me, so I didn't really go into details with them. I was still trying to understand myself-- not really clear on the technicalities.*"

Until the point of recovery from his illness, Peter remained selective about whom he chose to confer with regarding his illness experience, limiting it mostly to his psychiatrist and family members.

Fears

Because of the shorter period of time Peter's lived with a mental illness, his fears and concerns were not as abundant as John's and Alexia's. His main fear was about the specific panic symptoms and not understanding what was happening to him. His second main fear or concern was the stigma associated with a mental illness.

In having his first panic attack during his trip to Florida, he became so frightened that he called his mother immediately:

> *Okay. The first incident I remember actually was a panic attack, or things that kind of set me off. I was in Florida, and my dad was in Toronto. I was in Florida with my girlfriend, and I was at a sports store and I looked up on the television, and at the Toronto Molson Indy car race a crew worker had died, and someone in the stands had died as well in an accident, and I just remember losing it--like I had to call Toronto from Florida and track down my dad in Toronto. I just thought it was him... He was at the race in Toronto, and I was in Tampa Bay. And I had to track him down, it took me a few hours to track him down. And I don't know what caused it (panic attack). It's just the first incident I remember, trying to track him down.*

Peter's second panic attack occurred in a university classroom during the beginning semester of his freshman year. He recalls feeling so frightened that he escaped to the restroom in an attempt to calm himself. He was so fearful that he called his mother for support:

> *There was a washroom room right there, and there was a pay phone right across. So I used the washroom and then called my mother and talked to her, and she calmed me down. And then I went back to class. But, it didn't work, because like an hour later I would be walking around and the same thing happening again feeling 'what is going on with me?'*

Peter's second main concern regarding his illness was fear of the stigmatizing effect. He felt others would judge him, or think that he was weird should his illness become public knowledge. He consequently remained quite protective of how much and with whom he confided: *"they'd ask 'what's going on,' I'd say 'nothing'. I really thought others were judging me and thought I was messed up.* "

Peter's fear of judgement from others continued throughout the period of his illness. However, he did admit at the time of the interviews that should he, or any one that he knows, ever become afflicted with a mental illness, he would freely advise and encourage them to seek psychiatric treatment.

Symptom Experience

Depression and Panic Disorder

In speaking about his first two panic attacks, Peter describes how he felt at the time:

> *The first time was in July, and then that would be in the fall when I started university. It was my first year. I just started getting worked up, worried about things a lot more, and worried about not getting my assignments done. But I*

> *thought all this was normal that students found, worrying about not getting assignments done, not studying enough. I was in a program that I really didn't understand and I really didn't want to be in. I was in commerce. I started off in commerce, which was a big mistake.*

When Peter started to have panic attacks at school he believed that it had to do with school being too much for him: "*I just thought it was school. I thought I needed more time to adjust to university... I blamed university. I thought it was that that set me off...I thought I was the only one.*"

Eventually, Peter's feeling of both depression and panic symptoms extended to non-school settings where he was having crying episodes:

> *I just got to the point where I started to cry a lot more, there would be panic attacks of crying...just like, driving home, I would just kind of break down. And shows on television would make me cry-- you know, snappy things that would never have done that before. I just started to cry, and have these panic attacks, I was sad a lot and crying and I wouldn't have done anything about it but my mom and dad made an appointment with my family doctor, and said "you're going", and they drove me, they walked me into the room and sat there with me.*

Peter's reaction to his low mood, particularly his crying spells, made him feel very weak:

> *It's a bit old fashioned, but like guys weren't supposed to feel like this-- weren't supposed to cry...I thought I was weak, really weak. Really not going to make it in life...like I just felt weak and I felt worthless and my self-esteem was low. And I*

> *didn't want to be bothered with anybody else because I didn't think--you know, I deserved to be with anyone else.*

In terms of how Peter experienced his depression, he said: "*Very dark, sad-- waking up every day or not wanting to wake...but not wanting to give up. I had to push myself--exhausting, I just felt like collapsing but still kept going. I always got self going.*" Peter experienced great difficulties in coping with his depression and panic symptoms, voicing that he would have rather had the flu because of the mental pain and challenges in overcoming his mental illness.

Peter felt he lost control of himself mentally when he was hit with depression and panic symptoms: "*That would be the way I would describe it, just having no control, like a prisoner, being forced and kicked around by panic.*"

In recovery from his mental illness, Peter described himself now as: "*Becoming not cooped up or caged up, controlled by this sickness, and now, freedom, relaxation, happiness, life.*

Experience of Treatment

Therapeutic Relations: Family Doctor and Psychiatrist

Peter's experience with treatment includes his contact with both his family doctor and psychiatrist. His experience of psychiatric treatment was limited to his relationship with his family doctor, psychiatrist, and medication therapy, since he never was hospitalized for his illness. Because his experience with treatment is less (in terms of time) than others in this study, not as much information is offered by Peter on this topic, and thus is discussed together as one section.

Peter's first contact with a medical professional was with his family doctor. Because his family doctor provided supportive counseling prior to his contact with a psychiatrist I included this contact as part of the therapeutic relations section. He described his relationship with his family doctor: "*He was like a friend and I could tell him anything*."

Peter felt his family doctor was quite supportive of him throughout his illness, fulfilling the role of a mental health provider in the form a counseling relationship. Even though his doctor was often quite busy, he always made time for Peter spending anywhere from half-an-hour to an hour with him on a weekly basis. Eventually, his doctor did prescribe an anti-depressant medication for his depressive symptoms, however the medication did not take effect until he was in treatment with a psychiatrist.

Peter's first contact with his psychiatrist was in his first year at university at the age of nineteen. Although he reported feeling like himself again after one year, he stayed in treatment for approximately two years, lessening the contact as he convalesced. He described his first contact with a psychiatrist as a positive experience, feeling immediately comfortable in the relationship. He recalls his psychiatrist having a very positive and optimistic attitude towards his recovery. This was very reassuring for him since this was his first experience with a mental illness, not to mention his first contact with a psychiatrist.

In Peter's first therapy session his psychiatrist reassured him he was curable. He drew out on a board a treatment plan for him, explaining what needed to happen and what to expect. This included information about his diagnosis, medication therapy, and time frames in terms of when he could expect to start feeling better. He recalls his psychiatrist telling him he wasn't even close to being incurable stating, "*like I wasn't a lost cause, that I was very treatable, very treatable actually, he assured me.*" He admitted to feeling better immediately in response to the positive reassuring attitude of his psychiatrist.

Peter felt very much a participant in his treatment plan. He attributes this to the way his psychiatrist involved him in decision-making regarding his treatment of medication and psychotherapy. For example, his psychiatrist let him control what they would talk about in the therapy sessions, or when and if the medication needed to be changed. He states, "*I had some control over treatment. He'd ask me, 'what do you have on your plate this week?' or 'what do you want to do...he let me have some of the control.*"

Even though Peter had reservations about seeing a psychiatrist in the early phase of his illness, he reported having a very positive experience. He now agrees with the idea of receiving psychiatric treatment for emotional or psychological problems and says that he will do so in the future if needed. Furthermore, he said he would feel comfortable in recommending a psychiatrist to friends or family who might experience mental health problems.

Concept of Mental Illness

Peter shared John's views on the chemical imbalance theory of mental illness, at least in the case of depression and panic disorder. This resulted from the psycho-education he received on the causes of depression and panic disorder in treatment with his psychiatrist: *This sickness is like every other. You can see a doctor and be fixed. The only part that is different is that it has to do with your brain and your behavior and things like that.*

Elaborating further on the brain and behaviour relationship, Peter comments on the difficulties in managing the interactive effects of theses two components:

> *I found it a little bit more painful like I would rather have had the flu or something like that than this, but it's a little bit more painful, a little bit more challenging to overcome, but it is curable and it's a sickness just like every other one.*

Reflections: Mental Illness

Self Concept and Perceptions

Peter's illness had progressed to the point that he often found himself in tearful states to the point of having to remove himself from others. Although he was unable to control this and was well aware of how badly he was feeling, he had great difficulty escaping the stigma associated with a male crying, further compounding his sense of guilt and negativity associated with his depression. He felt like he was not allowed to experience depression because of both the stigma of the illness, and the stigma associated with a male being vulnerable. This further compounded his already confused and tormented state of mind.

Peter's view of his depression, the crying episodes, and the negative feelings associated with his illness was that of embarrassment. He believed it was okay for women to get depressed, but not a male-not him. He states: "*I was taught women are--it is more acceptable for women to be depressed.*" His negative self- concept of himself because of his illness is spoken to in a previous quote at the bottom of page 104.

Peter still thinks it seems funny for a guy to cry and feel depressed because of society's expectations and role identifications of males. However, he now believes that it was important for him to talk about his illness and get it out in the open.

How Peter views himself and how his life changed following recovery from his illness provides an interesting contrast to his original view as stated in the quote above: "*I like myself now and [life] is going really good and I'm hanging around my friends now and school is going good. I don't think actually it's ever been better.*" In asking Peter if life is different now in terms of what is going on around him, or if it is a matter of having a different state of mind, he responded:

> *To answer your question, I would say definitely nothing has changed in the outside world, but my state of mind has changed... Now that my state of mind has changed, I do want to do all the things I used to. Like in particular, I was really proud of myself when I decided to go to Boston with a guy I work with. We had a couple of days off. Like I would never have done that, ever. I would have talked myself out of it, but I didn't think about this at the time.*

Peter not only changed his self-perception, but his attitude and interest in life became more positive as his depression decreased. He went on to explain that recovery from his depression made him stronger mentally, enabling him to deal with a lot more. In asking him to speak to the change in his perspective from the time of illness to recovery, he said: "*It's like opening a door--like getting out of prison, I guess.*" Additional reference to this experience was expressed in a quote in the middle of page 105.

Losses and Frustrations

Peter feels that when his depression set in he felt like a different person undergoing a major personality change, a person who has lost complete interest in things he once enjoyed. This loss of interest sometimes extended to life in general, where he experienced such a sense of hopelessness that he had suicidal thoughts. Although he never made any actual suicide attempts, he admitted to sometimes stopping at a bridge on his way home from work and wondering if he should just jump and end it all. Fortunately, he realized how much this would hurt his family and still had hope that he would get better.

In terms of his professional responsibilities, he experienced great difficulty in completing his university exams, resulting in failing grades and an unsuccessful first year. He was unable to concentrate, or focus enough to complete assignments, which further fueled his anxieties, depressive feelings, and sense of hopelessness.

The fact that Peter chose to attend a different university than his friends (in an effort to not be distracted) isolated him further from his regular support system. However, upon recovery, he experienced a major change in his attitude toward school, where he no longer worried about his performance, and was able to complete assignments and exams successfully.

Peter also experienced a sense of stigma with his mental illness that was quite frustrating for him. His first response to his diagnosis of depression was: "*Oh my God, crazy people go to [psychiatrists]...I must be crazy...what am I doing?*" His first image was from that the film "One Flew over the Cocook's Nest". In fact, upon diagnosis of his mental illness, he reports feeling "*worse*" because of the media images associated with depression and mental illness. He was especially embarrassed at having to take medication (anti-depressants) for his depression and panic symptoms, refusing to disclose this to his friends because he feared he would be judged and that they would think him "messed up. "

Relationships and Isolation

As stated earlier, Peter's first experience with mental illness symptoms occurred in a classroom setting at university. Unfortunately, this deprived him of his peer-support system when it was most needed. In looking around the classroom setting, he remembers feeling very alone, isolated, and like an outsider. The worse his mental illness symptoms became, the more he tended to isolate himself.

Peter denies ever alienating himself from friends in the past, describing this as very uncharacteristic behaviour for him; however, this isolation became a common occurrence as his symptoms progressed. He admits to not even wanting to be around others, saying: "*I didn't even want to bother with others.*" He experienced both a lack of interest and a sense of not feeling like he deserved any attention. In fact, when others attempted to support him, he purposely pushed them away.

Peter also experienced a change in a romantic relationship and believes his illness contributed to its deterioration. Due to the time-constraints on him at work and school, and the stress of his depression and panic symptoms, he felt unable to maintain the responsibilities of a personal relationship and eventually discontinued the relationship. He expressed some guilt at how he handled this breakup: "*I didn't have time for her anymore, which I look back and think, wow, in a way I was a jerk, but I just had to do some stuff*".

In terms of Peter's relationship with his family, he also pushed them away for a while often isolating himself in his room when he wasn't working or at school. He now realizes how much his family was trying to help him at the time, but for reasons already discussed, he had great difficulty in accepting this support. Fortunately, he was able to accept the support of his family, friends, and mental health professionals in the later stages of his illness.

Insights and Awareness

Peter believes that the teaching and education he received from mental health professionals about his depression and panic disorder was one main insight gained from his mental illness experience. For example, learning about the chemical imbalance component of depression proved to be a great relief to him, allaying his fears and concerns about feeling like some kind of weird crazy person.

The support and attention from both family and professionals was another important point of awareness Peter developed following recovery of his illness.

> *Well, at the time I didn't realize the effort, the collective effort of everybody while trying to help me get better. With these interviews I've gone back and I've realized how my parents have helped me and my friends tried to help me. My family doctor and eventually DR. ZZ and the psychiatrist, how everybody pitched in and helped me.*

It wasn't until Peter was fully recovered from his illness that he could appreciate the efforts of all involved in his care and treatment:

> *I didn't realize it. When I was fully healed, I guess I had an idea, but now these interviews I can look back and say, wow, they really tried hard, I can see that. They wanted me to get better.*

Peter feels his experience with a mental illness will always be with him and something he will never forget. In telling a friend about his decision to participate in this research study he recalls the negative response he received. She expressed concerns, wondering why he would want to talk about his illness so openly. She compared his participation in such a study to talking about a person's death, the entire time suggesting he should just move on and put the episode behind him. He responded:

> *When I am older and I look back on my life, I will never forget that part. So, I mean it's always going to be part of my life, I might as well talk about it and explain it to help somebody eventually, somewhere, some way*."

He went on to say that now that he is better he would be completely open to answering people's questions about his illness and his experience with mental health professionals.

Peter felt that he was ready to look back on his mental illness experience when he decided to participate in this study: "*Yeah, I was ready, I was ready to look back on it when I was done with DR. ZZ. I didn't not want to talk about it. If someone had a question, I always answered it.*" He didn't feel there was any point in trying to cover up his experience:

> *To get it out in the open and talk about it. Why cover it up? I covered up, and look where it got me. I kept everything inside. So, now I try to be more up front, more like this is how I think.*

Reactions: Others

When Peter's first symptoms of depression began, prior to any psychiatric diagnoses, he recalls receiving a lot of attention from others, mainly his family: "*I received concern from others, but I didn't want people's attention, didn't want pity...trying to scare me into getting better, yell, 'kick in the butt', but that wouldn't have helped either, they were genuinely concerned.*" Peter also recalls his parent's fear of saying or doing anything that might set him off, which served to only heighten their concern.

His parents were concerned about the deterioration of his mental status and were responsible for his first contact with the medical system making an appointment for him with his family doctor. However, he recalls his parents' initial reaction when the doctor said that he needed to see a psychiatrist: "*Well, my mom, my parents, like a psychiatrist, I believe they felt that this had gone way too far, or what's happening. They thought they were at fault, but they weren't.*" Peter said that others felt this way as well: "*We all thought like, wow, this has carried over to the next level. What's wrong?*" However, when Peter finally began receiving treatment from a psychiatrist, his mother felt a lot better about this.

Peter's family doctor continued to meet with him during a three-month waiting period before his first appointment with a psychiatrist:

> *Attention from my family doctor--different from the psychiatrist, my family doctor, I saw him once a week, he was like a friend, safer than telling others, nonjudgmental, safer, trained physician, not a psychiatrist, professional, but not a shrink.*

Because Peter was self-conscious about the stigma of a mental illness he shared very little about this experience with friends. He did try to explain the theory on chemical imbalances and depressive symptomatology to one close friend but to no avail:

> *Well, if you try to explain a chemical imbalance to people who don't have a clue...I told my friend, and he was like, 'what's going on?' and I thought he was going to beat me up sometimes when I told him what was going on, he looked at me like I had ten heads.*

Other than this one friend, Peter did not disclose details of his mental illness experience to anyone, and therefore says that he was not treated differently compared to when he was well: "*friends didn't know exactly–didn't treat me differently, knew something was wrong...but not exactly.*"

CHAPTER 8: DATA

ALEXINE

Alexine, a nineteen-year-old female, was the last to be interviewed in this study. During the interviews, she was living at home with her mother and sister and working at two part-time jobs. She describes herself as a perfectionist type who always has to be busy, and as someone who is easily bored. She spoke of feeling lazy if she doesn't compile a list of things to do every day. She has great difficulty relaxing. In fact, she typically will go to extremes with things before she can let go and relax. She spoke of going so overboard with her routines and fixations sometimes that she would become sick and tired of them to the point of giving them up altogether.

Alexine also describes herself as a "why" person, having to know and "analyze" everything that concerns her. She also thinks of herself as "borderline nosey," wanting to know everything about everything. As a child, she says that she was an assertive, headstrong, disciplined, regimented, and serious kid who liked to be well organized.

Alexine believes that her personality today is fairly congruent with her childhood personality, although she was shyer as an adolescent. In fact, as she entered her teen years she became more of a loner, avoiding friends and social situations. This behaviour intensified as her mental illness developed. Although she described herself as open-minded and friendly, she often rejected compliments from others doubting and downplaying her positive attributes.

One big difficulty Alexine experienced as a young teen was going through puberty. The body and weight changes she experienced at that time were a great source of stress for her. Having a very strong bone structure, she exceeded her peers in physical development. This distressed her in that she became preoccupied with her body size, particularly her weight. However, Alexine's first body preoccupations occurred long before she reached puberty. As a young child of five or six years old, she recalls having a fixation with how her clothes fit. She detested wearing tight-fitting outfits, particularly her pants. If an outfit didn't fit just right, she would throw tantrums, immediately disrobing. Her reaction to tight fitting clothes was so extreme that her mother took her to a child psychiatrist to have this assessed. She doesn't recall what came of this, but hates tight-fitting pants to this day.

Another significant period of body fixation for Alexine came at about the age of ten or eleven years of age. She relayed a story in which she became preoccupied with her abdomen, thinking it was too big and flabby. This motivated her to do hundreds of sit-ups to flatten her abdomen. She even recalls shopping for a girdle with her mother at age eleven in an attempt to flatten her abdomen. This was not easy for her since she detested tight-fitting clothing, yet her drive for a flatter tummy won over. She wore the girdles for about two years. Given the childhood events discussed so far, it is not surprising that Alexine was later diagnosed with Anorexia Nervosa (AN).

Alexine recalls the beginning stages of her self-imposed diet restrictions shortly following puberty. The more stress or perceived stress in her life, the more she would restrict her diet. This eventually led to her family doctor referring her to a local health centre. She said that the group just talked about food issues without using any labels. In fact, she did not associate herself with the AN label at all, preferring to think of her food and weight issues as just a little problem, certainly not AN.

Throughout the one or two years of Alexine's contact with mental health professionals (nurses, doctors, and occupational therapist) in the EDO clinic, she had varying degrees of success and failure with food restriction, compulsive exercise and weight fluctuations. Her food restriction and weight loss became so severe that at one point she required hospitalization for a four-month period. It was during this time that that Alexine came under the treatment of a psychiatrist. Even then she recalls not being given the anorexic label, but felt the concerns were communicated indirectly. She believes that perhaps the mental health professionals wanted her to figure it out for herself.

Alexine has not been hospitalized for her eating disorder since the one period discussed above, yet still struggles with eating disorder thoughts and behaviours, albeit much less so than when she was in hospital. She still requires the attention of her psychiatrist in working out issues of her EDO, but is much more focused on the origins, or why she developed AN and how she can overcome the illness. In spite of her ongoing issues with food and body size, she is the epitome of a healthy looking, vivacious, and interesting female with lots of spunk and energy for life.

The Experience of a Mental Illness

Diagnostic Label

Alexine had the most trouble with her psychiatric diagnosis, anorexia nervosa. In fact, she was not given a diagnosis until long after receiving psychiatric treatment. As mentioned previously, when she first began treatment with the eating disorder support group, the term AN was not used:

> *Back then I didn't have a diagnosis that I was anorexic. I just had trouble with food. I didn't feel like I had the stigma, or that I was labeled, or put into a category, it was just, well, you have trouble with food and so do all these other people. So, I didn't feel like I was singled out, it was just like I am not the only one who has these thoughts, and I acknowledged that I had problems, but I didn't think that I had anorexia or anything like that.*

In describing what went on in the eating disorder groups (discussed later in the treatment section) Alexine felt that it was "educational," defining and explaining eating disorders such as bulimia and anorexia nervosa:

> *But then there was so much denial, and it's so powerful. It was like, well, this sounds a lot like me, but it hasn't happened yet. It's hard to draw the line. There is a very fine line between getting yourself into serious trouble. I just kept pushing that and pushing that, and I'm not there yet. And then it took getting into the hospital to realize that I was there, but still had trouble dealing with the label.*

Even after Alexine was hospitalized, the pattern of denial continued:

> *After I was hospitalized and after I did develop serious eating disorder problems it became a bit of a gray area, like no one knew whether I was depressed before I became a full-fledged anorexic or the other way around. And I didn't really know myself because it was something that crept up so slowing. I mean I was always preoccupied with food, probably since age eleven, but it was just the way it kind of was. And there is not a point at which I can say this is when it actually started...it's kind of like the chicken or egg kind of thing. I don't really know which came first.*

It wasn't until some time into Alexine's hospitalization that she finally got the message that she had anorexia nervosa. However, she felt this was communicated in a roundabout way:

> *I think it was Dr. X, but I really don't know. It seems to me that it was a really long time when it wasn't spoken... and it was in a roundabout way. It doesn't even stick out in my mind--it wasn't a concrete thing. It wasn't a 'you have anorexia', it was more like in the middle of a conversation and almost kind of said really fast, like sneak it in there, so I think it was probably Dr. X, but I can't really remember.*

Despite the education, knowledge, and insight Alexine now has about her disorder, she still has trouble referring to her food and weight issues as anorexia nervosa, choosing to speak about problems with food and eating:

> *Because it (AN) seemed like such a, I don't know, I mean I never had any experience with any other mental illness. It was so concrete-- you have anorexia. I thought, well maybe not all my behaviours qualify me as having it. I mean it's a huge umbrella, right? I kept thinking that maybe some of my behaviours maybe don't qualify as anorexia. And just like I said, I just kept thinking I wasn't quite there yet.*

Stigma

Alexine feared judgement of her mental illness not only from her peers or outsiders, but also from her own family. One of the things she feared the most in sharing with her family was her irrational or distorted thoughts related to her illness. She was afraid that her own mother would think that she was weird:

> *There are so many weird irrational thoughts that go along with it (EDO). Sometimes you say to yourself, when you think them it doesn't seem that weird, but when you say them out loud, even when I say them to my mother, I almost feel like she is going to say 'whoa- you're weird'.*

Because of Alexine's concern of being judged by her own mother, sharing with peers was out of the question. In speaking about her irrational eating-disorder thoughts and her fear about her friends' judgements, she states:

> *So I don't even with my closest friends, I don't really talk about, well, I'm scared to try on my pants today because I don't think they are going to fit and I think I am going to blow up, and I think that my heart is going to get clogged and all that stuff, they'll just laugh, you know! They're not going to understand for one thing. They're going to laugh or they're going to think I am just weird. Another fact of life too, they're going to think, well, you must be really weird, and if I hang out with you something's going to happen, you know what I mean? And nobody wants other people to think that they're crazy.*

Alexine rarely talked about her mental illness symptoms with anyone but her psychiatrist and remains strongly guarded about the topic today.

Fears

Alexine's primary fears revolved around food and weight issues. She typically experienced great fear, guilt, and angst if she indulged in what she deemed as bad foods. Even worse for her was an increase in her body weight. She uses an interesting "door analogy" to describe her fear of losing control and gaining weight while she was in the hospital following a weight-gain protocol:

> *Because it is so concrete (weight gain). The door was opening and then it was shutting behind me, like I could go up but I could never go back down. I think that's what it is, it's because I had to go up and not back down of course. But that's how it feels to me and that's why it was scary, because it feels like you're losing control because you can go up but you can't go back down. It's like a door that opens one way, but it won't open the other.*

Alexine's offers the following overall picture of her issues with weight:

> *Me and weight – it's like something that is going to catch me--like a flu--its like I am running away from it on a treadmill and its going to come up and bite me! And then I am not going to be able to fight it off...fear of something that is going to plague me.*

When Alexine first joined the eating disorder group prior to receiving the AN diagnoses she expressed fear of picking up bad habits from participation in the group work: "*That was one thing that can be scary--picking up others bad habits. I didn't pick up any other bad habits, but comparing, yeah.*

Her fear with body issues, mainly weight gain, began as early as puberty when she was undergoing a lot of physical developmental changes. Because she underwent some of these changes faster than her peers, and consequently weighed more than her peers, she thought she was fat, which caused her great angst.

> *I had body image trouble since age eleven-- went through puberty early and knew that the changes were coming- body changes, but I didn't expect to gain weight...weight jumped up quickly and unexpectedly and of course I'd blame it on myself.*

When Alexine was hospitalized, she had to abide by specific protocols to help her gain weight. She talks about her reaction to the protocols:

> *It was if you do this for us (because I didn't feel like it was for me- it really didn't seem like it was for me, it was for somebody else out there), by being able to do that I could get my mind off of some of my problems but it was scary because it made things all the very concrete. Like I've said, like numbers and concrete things like that is sometimes anxiety provoking for me because I am very rigid. And seeing those was anxiety-provoking for me. It's difficult to explain and also difficult for me to understand. To see a grid and to see this is another step, it's like you're moving up, that's scary. That was scary...if it was enough to put you over a concrete line on a sheet paper, that was like, wheww!*

Another anxiety provoking experience for Alexine is when others made compliments, or commented about her body:

> *It's not like it happens very often, but once in a blue moon, somebody says you have a good body, or you're thin or whatever, I don't take it as a compliment. I just get scared that I might not be able to keep this up forever and it scares me. Instead of saying thank–you, I just think what if I can't keep it up forever and it gets me scared.*

Even when a family friend once gave Alexine a compliment about how she looked, her first thought was that that must mean she had gained weight: " *My interpretation was, oh God, looking good equals 'you've gained weight.'* "

Alexine also expressed her fear of having to normalize her eating habits at some point in the future:

> *I just think that there is going to be a time when that (eating disorder) will have to stop. I can't keep that up forever. At some point I am going to have to start eating properly again, and that is just going to scare me all the more. That is what I have to remind myself... If I've been doing it on a daily basis and I get used to it, it's not as scary. It's still anxiety provoking, but if I do it everyday, than I will start to get the idea in my head that nothing is going to happen to me. But if I haven't been-- and all of a sudden I start eating properly again and I am going to gain weight because it is just inevitable, than that's going to be really scary. And not only that, that's getting back into the extreme again.*

Alexine also experienced fear when she realized how much time and energy she had allowed her eating disorder to consume:

> *Missing a lot of life. Although this is really scary for me, and although I don't want to let go, and maybe it will be a long time before I let go completely, but I'm missing a lot of life and there is no room for anything else. It's funny, sometimes you don't even realize that...I remember a couple of times it would hit me, is this all I'm doing, and it seemed like a job or something. Like what else am I other than that, and that kind of scared me.*

Symptom Experience

Anorexia Nervosa

Alexine experienced her eating disorder as exercising some dysfunction in her thought processes. She described it as someone's imagination running away with them:

> *For me that's what it was. Irrational thoughts about blowing up and getting really fat and dying because my heart was clogged and that kind of thing. My*

> *imagination would just run away with me and it wasn't based on real life, or facts, on what is and what is not normal, what really does exist.*

With respect to distorted thoughts, Alexine had this illusion that people she hadn't seen in a while would always think that she had gained weight. Another interesting, but distorted idea was that if she noticed others had gained weight, a friend for example, that meant she too must have gained weight. This was especially prevalent if she hadn't seen that particular friend in a long time:

> *One thing that does scare me is seeing people I haven't seen in a while and they're going to think I've gained weight and that is the thing that really scares me, like a big fear of mine, but not the first thing I notice about them.*"

Prior to developing anorexia nervosa, Alexine thought of her diet changes and exercise habits as somewhat of a healthy living style, but she eventually realized how those thoughts can take on a life of their own:

> *Motivation and power, all those good things, but then it is not will power that is driving you anymore, it's like it has its own voice. It's not I will go exercise and I will do this, it's almost like you don't have a choice. It's like another little thing inside you that's doing it and it's not you.*

It was very difficult for Alexine to turn off her irrational thoughts about food and weight. She believed in her heart that she would blow up to an unimaginable size if she ate certain foods, or certain amounts of food. At the time, she denied feeling any disconnection with reality, or any experience with irrational thoughts about food and weight.

Alexine had ongoing battles with the weight scale at home, often weighing herself many times a day, yet always doubting its reading. If the numbers on the scale did not meet her expectation, she often attributed this to some malfunction in the scale. Only recently was she able to get rid of the scale in an attempt to curb her compulsive need to weigh herself. This was necessary to alleviate the negative thoughts and stress associated with the weighing process.

Constantly weighing herself was a catch twenty-two for Alexine. If the scale read higher than expected, she would become anxious and fall back on her restricting behaviours. Even when the scale met her expectation she still felt the need to restrict in order to maintain the loss of weight. When she didn't succeed in controlling her weight, she commented:

> *It's frustrating when I work and work and control something and want certain results and I don't get it. Like especially controlling what I am eating and finding out I gained weight--that's a real serious piss-off. Look what I've done and tried to do and nothing happened.*

When Alexine succeeded in controlling her weight to her satisfaction she experienced a feeling of relaxation and a sense of freedom. On these rare occasions, she would allow herself to eat a little more, or have some special treat that was not part of her strict diet plan. Nonetheless, this feeling was usually short-lived. She took care not to relax too much for too long with her diet and exercise. She felt this would result in weight gain, which would lead to negative emotions such as depression:

> *When there is room to gain--like when I was in hospital-- you've got this window of space-- what made me feel safe- that's why I tried to keep my weight down*

> *because I knew I had that space —in case anything happened--I knew I had a little protective--give and take, so when suddenly that goes away and I try to normalize my life and there is no give and take-- and I am there where I should be-- I get really scared... and restrict.*

Alexine experienced a great sense of psychological control from controlling her food and weight. She had this sense that having control of her weight somehow made up for lack of control in other areas of her life. Eating unacceptable foods or gaining weight often left her feeling very bad. She described herself as feeling fat, gross, and out of control for indulging in such behaviours.

> *It's, well, something will be in control at least. At least when things start getting better, or when skies start getting brighter, this part of me will be ok and taken care of. It's almost like I can envision the future, I have other things in my life and then I have my body, myself, my weight, as all one thing. If this is taken care of, if I can control this, and other things start coming up, then things will be perfect. I will have both components. It's like two sides coming together.*
> *It's like if I can control this, then everything else will be ok...even if some things aren't making me happy right now, at least I have this...it's more like if I have this, at least I have this. That what I think. That's more like it, not like this will make me feel better...this is more like a feeling that if I can control this well than I have some control over my life.*

Alexine often-experienced mood changes in relation to her food, weight, and diet control issues. Depression was the most frequent emotion associated with her eating disorder: "*If I am depressed right now and I stuff myself and I don't work out and I gain weight or whatever, that will get me even more depressed.*"

Although Alexine eventually gained insight into her illness, acceptance of it was slow to come. In fact, to this day, she shies away from using the label anorexia nervosa to describe her mental illness experience. She spoke of downplaying the situation a lot even up until the point of requiring medical attention. She did this with her family doctor, telling him things weren't really that bad, forever reassuring him that she was fine:

> *I don't even know what I would have said if I was confronted with it (i.e., anorexia diagnoses). Depending on who it was...I would have said I don't think that I'm there yet...I think I wanted help of some sort, but I didn't want the full-blown 'wow, you have an eating disorder and you need a full team of specialists surrounding you.'*

Experience of Treatment

Therapeutic Relations: Psychiatrist and Mental Health Workers

Alexine was treated by various mental health professionals including: a psychiatrist; psychiatric nurses; and child and adolescent mental health workers. All three types of mental health providers were involved in her treatment from the beginning stages of her illness. Most of what she shared about her experience with psychiatry is discussed in the section on her hospital experience later in this chapter. She did not receive any medication, or invasive therapeutic treatment regimens, thus a separate section on treatment modality is not presented.

Alexine first received psychiatric treatment from an eating disorder clinic designed to educate and treat such illnesses. Her experience with this was positive from the standpoint that it offered her some comfort when she realized she was not the only one suffering from eating disorder symptoms:

> *It was an encouraging environment...it was just talking about your experiences, and this is what anorexia and bulimia are as far as a definition, but just tell us about what happened, but we're not going to tell you what you are. They were hoping you would pick up on that yourself.*

Alexine described her experience with psychiatry as quite positive. She did not have a problem talking to the mental health professionals and preferred this to sharing her troubles with friends or family. She did not feel strange or weird about going to the psychiatrist, saying "*I'd joke about it and I'd say 'well, I had an appointment with my shrink.*'" She strongly believed that only a professional could help her with her personal issues, believing that her friends or family would be biased:

> *And because they (health professionals) are educated in that way they know more about human behaviour than maybe your friends do, so I mean people always say, 'well, don't you have anyone else to talk to?' Well, but first of all just about everybody who is connected to you would be biased in some way about certain things. They don't know, especially about eating disorders.*

Alexine experienced her psychiatrist and other mental health professionals (psychiatric nurses) as objective, non-manipulative, and quite helpful with their knowledge and advice. Nevertheless, she has and continues to experience some frustration with her treatment because she is not completely rid of her eating disorder thoughts. Although she attributes most of this to her own denial and resistance, particularly in the past, she wonders if she requires more from her psychiatrist. In speaking to her own denial and resistance to the treatment and the feedback from mental health professionals in the early stages of her illness, she says:

> *It was denial. That was another thing. I didn't really listen to it. The fact that I faced is I was denying it. It was just kind of like, well, you're denying it, but we're not going to talk to you about it. We're just going to tell you how it is.*

Alexine did not want to share any underlying issues related to her eating disorder with her psychiatrist and mental health workers because of the comfort and sense of control it offered her:

> *I just don't talk to them about how it started and different things that I do, stuff about why I do it, like how it makes me feel protected, or makes me feel like I am in control. Those things never really came up. At the time I just thought these things would blacken my issue and I thought this was separate from my mental stability and I saw it as something separate and now I know it's not. It' so intertwined.*

Currently, Alexine visits her psychiatrist approximately once or twice a week. Although their earlier focus was on childhood issues, she now wishes to focus more on underlying issues related to her mental illness. She craves to know the "why" of her illness: "*I still haven't really gotten down to why I do this, because the personality thing is like chipped into my brain.*" Although she realizes she has to do her own work in getting better, she wishes her psychiatrist could help her more in terms of understanding why she is like she is.

Hospital Experience

Alexine's most difficult time with her illness and treatment came during her hospitalization experience. She struggled the most with her illness at this time since she had to abide by certain treatment regimes, or protocols that were in complete opposition to her ideas and behaviours. She recalls her first experience with her admission to hospital in which she had to be admitted to a medical unit for approximately three days because of her self-induced starvation. She describes this as her near-death experience:

> *When I first came in I was on a medical floor. I think it was three days-- I'm not sure. I was thinking it was three days because when I first came in they told me I was jaundiced and gave me pediolyte and everything, and they said, okay, we're going to whip you up stairs. And I remember sitting outside in the hall and saying 'I'm never going to do this again--I'll eat, I'll start right now,' and thinking that everything would be different. Well, part of it was bargaining, but part of it was, I thought this was my near- death experience kind of thing.*

Once Alexine was medically stable, she was transferred to the in-patient psychiatric unit where she was hospitalized for approximately four months. She experienced a lot of stress and frustrations during this time in everything from her own food and weight issues to her relationship with staff.

Her first day on the psychiatric unit she recalls feeling misunderstood, as if the staff didn't know why she was in hospital, because they expected her to go eat with other patients in the unit kitchen:

> *Well, like I said, the first night I was there they just said well, okay, its dinner time...I guess it wasn't just understood that I really couldn't...and I said to my*

> *mom, I said you know it's almost as if...I almost felt like the chart had been passed around and nobody knew why I was there. That's how I felt, but I know that's ridiculous. That's how I felt-- I felt like nobody knew why I was there.*

Going into the kitchen that first night was a horrifying experience for Alexine. She had to leave and go back to her room:

> *Going into the kitchen that night. I can remember what I did. I think I went in and I talked to them and I said 'are you crazy?' 'I can't do this!' 'How do you think I got in here?' I just went back to my room and did something on my own and somebody came down and talked to me.*

In response to expectations of the staff in the early days after her admission to hospital she recalls thinking: "*And now you want me to sit in there with a bunch of crazy kids and doctors and strangers and people I don't know.*"

Alexine recalls feeling very lonely and isolated in the hospital. She felt that everybody else was crazy, that she didn't really belong there, and that her problems were not really being addressed:

> *I felt like everybody else was crazy and I was definitely different. I just felt so isolated. I felt so lonely. I didn't feel like my problem was really addressed because initially I was supposed to go into the kitchen, and I just had my tray there.*

Alexine also experienced the hospital environment as anxiety provoking because of the cues and reminders of why she was hospitalized:

> *Lonely, that's one thing, I felt really lonely, and one of the big motivators was when you talked about negatives like getting scared and getting anxious, that was*

> *like getting weighed once a week and talking about it all the time. I found that I couldn't get my mind off it. Here I was in the hospital and there were cues everywhere, reminding me of why I was there, so, I couldn't escape, couldn't escape the thought of it. So, that was anxiety provoking.*

Another problem Alexine had with the hospital environment was fact that it was populated with many young children at the time because there was no teen unit:

> *I was getting annoyed because everybody it seemed to me, except for two, were all younger than me, and I kind of felt at times like all the patients were younger because they didn't have the teen side then, it was all young kids. They had very different problems, and I thought 'why am I here of all places?' Isn't there somewhere else I could be, because going into the little lounge there-- I felt like I was babysitting or something. I didn't have anybody to talk to. I found it strange because I thought my problems aren't really being addressed and I am just being punished.*

Alexine was expected to follow a treatment protocol, which controlled such things as her diet, activity level and various other privileges. These were managed according to how much weight she gained or lost. Basically, if she gained weight she gained certain privileges such as more up-time, or a short walk with her family or staff. However, if she lost, or didn't gain the expected amount of weight, then such privileges would be revoked. She viewed this privilege-based system as a form of punishment. Alexine believed the protocol was more to satisfy the staff than to treat her eating disorder, stating:

> *It was if you do this for us--because I didn't feel like it was for me--it really didn't seem like it was for me, it was for somebody else out there, by being able to do that I could get my mind off of some of my other problems.*

Alexine describes her feeling of being punished and not having her problems addressed by the treatment staff during hospitalization:

> *I'm punished because this is terribly boring and it's anxiety provoking, and I don't really feel like I'm resolving, or like I'm getting to the reasons why I do this and hell if you don't like this do something about it. It was just like if you don't get your weight up, you're not going to be allowed to do this.*

Overall, Alexine believes the eating disorder treatment protocol was a bad strategy for her: "*They were bad strategies I think initially. Well, things got changed I guess, I mean everybody can't be treated the same I suppose, but they were bad strategies for me and maybe they wouldn't be for somebody else.*"

Alexine experienced most of the nursing staff and mental health workers as supportive in terms of being attentive to her expressed needs. However, not all the staff would address, or initiate conversation about her eating disorder. There were usually only a few specific staff members that would spend any time going into these issues. Some members acted more as a social support—playing board games, or engaging her in extra-curricula activities when she was not engaged in any formal treatment. In some regards, Alexine found this a bit of a relief, or a freeing experience from her eating disorder issues, saying: "*So it kind of did give me a little bit of freedom.*"

There was one nurse she felt was rather strict. Yet there was always another staff member whom she experienced as being the opposite, so overall she did not have any real negative feelings about the way staff treated her. As discussed earlier, any of Alexine's negative experiences with treatment typically had to do with the treatment protocol versus the treatment team. However, because the treatment protocol was implemented by her health care providers, Alexine's negative experiences in treatment sometimes were experienced as negativity towards the treatment team.

Concept of Mental Illness

When Alexine was first diagnosed with AN she had great difficulty in accepting that she even had a mental illness, let alone an eating disorder, seeing her eating habits and preoccupations as separate from her mental stability. Her specific thoughts on this matter are expressed in a previous quote found in the middle of page 120. She admits to wanting some help at the time, but experienced great difficulty in accepting she had a mental illness in the form of an eating disorder, stating, "*I think I wanted help of some sort, but I didn't want the full-blown 'wow, you have an eating disorder and you need a full team of specialists surrounding you.'*"

When I asked Alexine the specific question, "what does mental illness mean to you, what does it bring up for you?" she replied:

> *It means being detached from normal ways. I guess being unsure of how things should work, or the word you said before that--that I was really comfortable using was "maladaptive behaviour,"-- not being able to cope with duties and work things through-- irrational, uncontrolled fears. It's really, I guess, it's so ambiguous and so widespread it's really hard to say.*

In reference to her own illness, Alexine states:

> *The biggest thing I think of is someone's imagination running away with them. For me that is what it was. Irrational thoughts about blowing up and getting really fat, or dying because my heart was clogged and that kind of thing. My imagination would run away with me and it wasn't based on real life, or on facts of what is and what is not normal, what really does exist...your mind gets away from...and it's hard to bring...just like generally speaking, it's hard to bring someone who has a psychiatric problem back to the real problem at hand. It's always somehow distorted. The mind somehow distorts what really is.*

Alexine viewed her anorexia nervosa as a misguided behaviour, or a bad way of adapting to things. She states: " *I saw it as a misguided behaviour, but I didn't see that there could possibly be underlying issues that led to that. I didn't see that there were parts of me that were perfectionist.* " In the developing period of anorexia nervosa, prior to any acceptance of her eating disorder, she perceived her eating disorder thoughts and behaviours as a health-conscious thing:

> *There was a sense that for the longest time I thought that I could control my eating and my weight, but not have it control me, or not have any kind of serious problem. It would just be a healthy awareness of my body and food and that kind of thing...so I was still kind of thinking well, I don't have an eating disorder, I'm just very health conscious. So, it starts to creep in and it gets worse, so when they're saying okay, you're here, it just kind of crept up on me while I was sleeping. Well, I wasn't sleeping, I was still thinking that I was here... I am trying to think of another word for it, but it was like defeat. It was like giving into, okay, well, I did mess up.*

Shortly before Alexine was hospitalized for her AN, she actually managed to eat a little, prompted by her mother's request. Because of this, she thought that since she had eaten something, then how could she possibly have an eating disorder like anorexia nervosa because people with AN can't eat at all. Her extreme all-or-nothing thinking contributed to this perception:

> *I can remember thinking three days before I went into hospital, 'I'd had a good supper,' although there were times when I hadn't been eating. So it was just kind of a break in there. I felt OK about that, which I think was partially because I was just so starved that this seemed okay. I thought maybe, yeah, I can eat, and two or three days later I was in the hospital anyway. So that made me think, 'well, this can't be, because people who have anorexia can't eat period'. That's what I thought.*

Alexine's perception of her body and weight also interfered with her ability to accept her mental illness:

> *And there were a lot of things that made me deny what was going on. The fact that I had eaten supper three nights before, the fact that I was 105 pounds and I didn't really look sick, but I didn't look like what I thought someone who was anorexic was supposed to look like, or someone that was hospitalized. But one of the things that really hit home was having to take Pedialyte and being told that I was jaundiced. The fact that I was messing up my liver and stuff was enough for me to say, okay, something is going on here.*

Alexine's initial experience in hospital influenced her ability to accept the fact that she had a mental illness. Observation of abusive, violent behaviours in one of the patients as well as unusual behaviours in others fed into her denial patterns because her symptoms were so different from those other patients. Observing such behaviours made it difficult for her to categorize herself as being mentally ill:

> *I thought, what? I just couldn't see the connection, I couldn't see how it (AN) was at all related...I was thinking 'mental health, mental illness, yeah I have trouble with food and yeah I have these crazy thoughts about getting fat, but what the hell is this?'*

To gain a better understanding of what mental illness is and what it entails, she adopted the attitude that it is an illness of the mind versus an illness of the body. Nonetheless, she still has trouble totally accepting that she had a mental illness:

> *So I started to get a better understanding of what mental illness was and what it was composed of and how varied it can be. A mental illness is almost like saying like, if I had a physical disability, it could be so different, there are so many different things. It doesn't mean that one could be more severe or less severe, but different. That's what it is, it's obviously not an illness of the body. It can lead to an illness of the body, but it is an illness of the mind. So therefore, what else are you going to call it? I just kept thinking that I was maladjusted, or I wasn't adapting to the world or I couldn't cope.*

Alexine still asks herself: "*Did I really have an experience with anorexia, or did I just have, you know, what was it--but I should probably view it as anorexia--that's the thing-- its just downplaying- do you know what I mean?*"

Reflections: Mental Illness

Self Concept and Perceptions

Alexine experienced a lot of negative feelings towards herself as a result of her illness. One experience that was particularly bothersome for her self-image was that of going to the gym. She spoke of gym cues, like a scale, posters, or a sense of competition, making her feel badly about herself as if she didn't measure up. She also spoke of the constant affirmation she needed from others. For example, having a boyfriend to her translated into her not being fat. She often derived self-acceptance of her body based on the acceptance of others. Nonetheless, she resented needing this outside acceptance in order to accept her own body.

Another area of difficulty was the extent to which Alexine allowed her body weight and appearance to control how she felt about herself. In other words, if her body and weight met her standard for the day she could feel good, relax and maybe even eat more. If her body and weight did not meet her standards, she would punish herself with self-loathing statements, food deprivation, and a strenuous exercise regime.

She also struggled with comparing herself to her mother, whom she described as petite enough to wear a size two. She described feeling both jealous and angry toward her mom, constantly asking herself why she couldn't look like her. She recounts an experience in which her mother gave her a pair of jeans because they were too big for her. Her feelings about this were: "*She gave me these jeans, and I couldn't fit into a pair of my Mom's jeans...I remember feeling 'I am gross' I can't fit into [my mother's jeans] I must be fat--I couldn't cope with that.*"

Initially, Alexine thought of her illness as something separate from herself. However, upon reflection, she now believes that her eating disorder or illness was intertwined with her personality. With this insight she now has the desire to examine the underlying issues related to the development and course of her illness, saying, *"I think that is one thing that I'm looking for now."* She believes her inquisitive and "borderline nosey" personality is a motivating factor in seeking answers to her illness. Being a "why" type of person she hopes to find the answers to her illness in an effort to get on with her life. She often wonders where life is going for her and what her future holds.

Lack of self-trust is another area where Alexine struggled. She spoke of her insecurity, and lack of trust in her body to manage itself, and she often deferred to others to validate her weight: *"I have started to think...I shouldn't look outside at others to see what they are seeing of me."* She believes her lack of self- trust (in her body) has played a significant role in the development and perpetuation of her mental illness, making it very difficult for her to reach full recovery from an eating disorder syndrome.

When Alexine reflects on the time and energy consumed by her illness, she cannot imagine her life with it. Nevertheless, she cannot imagine going on like this (AN) forever: the struggle between the *self* with food and weight issues and the *self* without food and weight issues is obviously still very much an issue for her.

Losses and Frustrations

One significant symptom of Alexine's illness was how much of her life was consumed by her illness. She describes it as taking up a lot of brain space leaving little space for personal and social activities and other positive experiences:

> *I didn't really face the fact that I was losing all my interest, dreams, abilities and everything was being traded for the [eating disorder]. I thought, gosh, there's nothing but the eating disorder now. Although I might never get rid of the thoughts completely, I want to be the kind of person that I'd like to meet, to have interesting things to say, so that was a big wake-up call for me.*

Nonetheless, she admits to being preoccupied with the details of her food and weight issues. Because she still struggles with these issues, technically she is not fully recovered from her mental illness. This is another source of frustration for Alexine because she wants to be living a normal life without the eating disorder symptoms. She reports that her mother and sister have to remind her of progress made because she herself becomes discouraged so easily.

Alexine denies projecting blame for her eating disorder onto her mother. Instead, she wishes that her mother would understand how certain events served to influence her in the direction of an eating disorder. She feels that her mother and sister think she has tried to use her eating disorder to control them. This is not her experience, and she feels great frustration with her mother's negative perceptions.

As with the other participants, Alexine felt the stigma of her illness. She described her friends as being 'weirded' out by the fact that she had a mental illness that warranted the attention of a psychiatrist. An interesting sidenote she shared with me was the fact that some of her friends were also seeing a psychiatrist. Initially, she expressed some concern over her friends thinking she must be weird, or crazy, with respect to her eating disorder thoughts, but this was eventually resolved.

Alexine's most frustrating experience with a stigma was during her hospitalization. She was embarrassed that she was on a psychiatric ward and by the other patients' behaviour:

> *I felt embarrassed to have my friends come in and stuff. Just to tell them that I was on the mental ward and that kind of thing, because it seemed so different. I felt everybody else was crazy and I was definitely different.*

Relationships and Isolation

Alexine experienced relationship difficulties as a response to her illness. Because eating is very much associated with social events, she had no choice but to avoid social situations that involved food. This left her feeling isolated and disconnected from others. Nonetheless, she believes her angst and self-consciousness about eating and weight are completely responsible for her social avoidance. She admits to letting her friends slip away, allowing herself to "drop out of the loop", making herself feel even more like an outsider and a loner:

> *Well, it (AN) was changing my life around and avoiding situations where I might be forced to eat with a group of people...or not going out with friends who were going out on a Friday night to get a pizza...so, then I was missing out on a whole bunch of things...it was missing out on the social aspect of it...like going to the movie that might follow just because I didn't want to do the first part.*

The impact of Alexine's illness on her relationship with her mother and sister was similar in terms of avoiding social events so that she could also avoid food. She started to feel disconnected from her mother and sister for this reason. Initially, Alexine reports that her mother and sister would pass off her eating disorder behaviours as being lazy, or shy, or having anxiety around other things unrelated to food. Alexine was able to conceal her food issues for a while because of her ability to make innocuous excuses for not wanting to do things, like go to the movies, or out for dinner.

Eventually her ability to conceal her eating disorder failed, and her mother and sister began to react to her with great frustration. This resulted in much conflict and frequent arguments that she now realizes were a direct result of her eating disorder. Alexine describes a typical scenario between her and her family over her food issues:

> *Initially, they [mom and sister] would think I have anxiety around other things, so...they would figure that's what it was...now they know it could be caused by not wanting to go (anywhere) because they might get popcorn and it might make me feel anxious because we'd just had supper and that was making me feel anxious, or something like that...of course, my mom always comes back with 'you can't control what other people do' and 'stop trying to control what they do,' and I'm saying 'No, that's totally not it--I'm not trying to control what you do and I would never try to do that...I'm just trying to tell you that that kind of situation makes me feel anxious and I just won't go--so then I get offended and my back goes up and I'm trying to tell her that this is making me anxious, so I just won't go...but she wants me to go, so there's a conflict.*

Scenarios like this were common between Alexine and her mother, creating a great deal of strain on an otherwise healthy supportive relationship. She eventually realized that her eating disorder was the culprit in these conflicts and is now able to work with these situations when they arise.

The last point of discussion regarding the impact of Alexine's eating disorder on relationships pertains to her feelings of isolation when hospitalized. Interestingly enough, this speaks to the underlying close bond between her, and her mother and sister. Four months in hospital away from her mother and sister's support left her feeling very lonely and strange. She spoke of the importance of their company, which always gave her some sense of support and comfort even in the worst of times. The hospitalization made her realize how much she valued and needed supportive relationships, especially the support of her mother and sister.

Insights and Awareness

Although Alexine continues to struggle a lot with her eating disorders symptoms, she shares a lot of insight and self-awareness regarding her experience with anorexia nervosa. In particular, she is insightful about the thoughts and feelings she experienced in response to comments made about her body. She could rarely accept any feedback from people about her body, especially if it was positive, because she often interpreted this as meaning she must have gained weight:

> *Because my grandfather's girlfriend actually as recently as this summer said to me when we were up at her cottage, 'you look so good, you look so healthy,' and I went over to my mom and I was just like...for me, I knew that meant you're eating better. I didn't want to know about it, I didn't want to think about it. I kind of wanted to go back to being in a cave where you know you're eight years old and you don't even think about what you eat. You know, and people don't comment on your body. You know it is going to happen, and I knew that it was going to come at some point and people were going to say things.*

She could rarely trust feedback from anyone, especially strangers, and still struggles with compliments when they come from anyone other than her mother, or close family members.

Alexine also spoke about the false sense of security, or confidence that her EDO gave her. Although controlling her intake and weight provided a sense of control and confidence, this was typically short-lived and quickly dampened if things became disrupted in any way: *"Restricting what I ate gave a false sense of confidence...it offers false hope, sometimes the opposite will happen."*

The opposite for Alexine would be a slight gain in weight. Consequently, she experienced extreme frustration and anger because she couldn't understand how her body could betray her by not losing weight, and even worse, gaining weight, especially after all her efforts to control it. It took her time to accept that she cannot control her body forever and that attempting to do so was not only a waste of energy, but was taking away from getting on with her life.

Alexine speaks to the irrational thoughts that accompanied her EDO and how this affected her reality:

> *One thing, I was so deep into my thoughts, I didn't think they were irrational, I didn't think that I was distorting the facts. I didn't think I was out of touch with what really was. I didn't think I was out of touch with reality because I really believed that these things would happen, that if I ate I would blow up, and all these thoughts that I had in my head, I didn't realize that they weren't rational... So it was kind of like I would like to get rid of these irrational thoughts and I*

> *know that the way that I handle myself around food and my weight wasn't normal and wasn't like most people.*

After many efforts to control and conceal these specific issues Alexine eventually realized that the EDO was controlling her: "*...I can't hide what I'm doing anymore, but what I'm doing is something that I'm not controlling anymore really, it's more like it's controlling me, and I kind of felt like a victim, like something came up and bit me.*"

She spoke of how much work was involved in challenging her distorted body-image thoughts. What worked best for her were concrete visual exercises that specifically challenged these misperceptions. During her hospitalization she recalls one specific exercise that was very helpful. This involved examining a poster of bodies arranged in various shapes and sizes and comparing them to her own body by selecting the one that was most reflective of her body:

> *I remember one time–seeing Dr. X and she had these posters with all different shapes and sizes...I had to point to the one that most looked like me...to look at it and judge for myself... things like that were really effective for me.*

She now believes that many of her efforts to control her weight, and food intake was like a lost cause: "*It's a lost cause trying to control your body, I can't control what its does, it's like trying to not go to the bathroom.*" In terms of trying to manage her weight to unreasonable extremes, she soon realized that she just couldn't do this forever:

> *I can stay at this end for so long and I can stay at that end for so long, but it won't last forever is what I am saying. I have finally come to realize that I guess. I'll feel bad about myself for doing this for too long, and then I'll do that for too long. I find it really hard, and I'm always wondering.*

Alexine spoke of how the EDO consumed so much of her thoughts and energy that there was little space for much else. This is elucidated in conversations she had with her psychiatrist:

> *And even talking with Dr. X about other things later on made me realize that it takes up so much of your life and so many of your thoughts, like I was thinking one time how many of my thoughts--because that takes way from other wonderful thoughts that I could be having, that are a part of me, that make up my personality, that make me interesting. It's almost like-- it takes away part of your personality, because you only have capacity for so much, and the more of it you allow in there, the less you'll have for other things.*

She described her realization of the impact of her illness on her time and energy as a wake-up call. She spoke to this earlier in a quote found at the top of page 141.

Initially, Alexine always thought that her eating issues had nothing to do with her state of mind. In fact, in the beginning stages of treatment she was reluctant to talk to doctors about her thoughts and feelings around food and weight. Her rationale for this had to do with the sense of comfort and control her eating disorder provided for her. She spoke to this experience in a previous quote found in the middle of page 130.

Alexine still plays with the idea as to whether she really had an eating disorder, or was it just a preoccupation with food and weight. This will always be an issue for her because of her concept of mental illness and her problems with the anorexia nervosa label. This sense is reinforced by the fact that she now feels quite different about herself compared to the beginning stages of her illness:

> *Do I have anything to say about this (AN)-- because I am totally different now and that's the thing, I think I am totally different, but I still have a lot of the same thought patterns and once I get talking I realize that I am not and I still have that in me. I try to talk about my experiences, try to be objective...try to separate it, well, from what happened, and how I felt about it then to how I view it now, try to see those as different.*

She went on to say that the interviews themselves added to her insights because they helped to legitimize her eating disorder:

> *You are interviewing me because I did have problems, I denied that...I am coming in to be interviewed for a real thing. It's wonderful how the mind plays tricks and pushes things out that it doesn't want to think about. The fact that you are interviewing me about information about this really legitimizes it.*

To summarize Alexine's insights regarding her eating disorder, she believes it was very much a form of procrastination, or postponement of facing other things in her life. Things like what she wants to be, or where she wants to live, or what type of relationships to have. Being focused on the EDO allowed her to delay decisions about life that she was not ready to make, yet still maintain some sense of control:

> *That's only a recent thing. I have only started to recognize that recently. I knew that the eating disorder problem was that, well, at least I have control over this, but by taking action and not procrastinating--I would procrastinate on a lot of things because I was too scared to do this--I would feel more comfortable--I have started to think that about my weight and about how I eat.*

Reactions: Others

Although Alexine's mother and sister were the two people she confided and trusted the most during her illness, they too had their struggles in relating to her illness. She speaks of their frustrations in thinking that she was trying to control the family with her eating disorder habits. When she began to avoid family outings because of her fear of having to eat, she evoked a response of frustration. This is spoken to as part of a quote where she describes a typical scenario between her and her mother over food and weight issues found on page 143.

Alexine herself experienced great difficulty with her mother's impressions, and felt hurt that her mother would think such a thing:

> *I would never say that, and it bothers me that she thinks I would try and manipulate her. So, then I get offended and my back goes up… she thinks that I'm trying to change the plan so that it will suit me, but that's not it. And so we come to an impasse, we can't really talk about it anymore, and she goes off feeling mad at me. Trying to get my own way, that's what she thinks--that I'm trying to get my own way and I'm totally not.*

Even though these conflicts did exist between Alexine and her mother, she was confident about how much her mother and family cared for her. She believed that they always had her best interests at heart. She recalls that the few days prior to hospitalization it was her mother who put the most effort into persuading her to eat something: *"For the last couple days my mom was begging me to have anything, like you know, just anything, because that was one-on-one with someone, someone I trust more than anyone else in the whole world."*

As far as Alexine was concerned, her mother could only be there as a support person, not as someone who could help her resolve her eating disorder. She did not believe that her mother, or any other non-professional, could really help her with her mental illness issues since they were not experts in the field.

She also received a lot of support from other family members. She recalls one incident where an uncle gave her a message card that was very helpful for her on one of her bad days:

> *I write things down in a little book-- inspirational messages. One day my uncle left this neat little quote on the fridge: 'call if you measure your self- esteem by calories.' He drove all the way out to my place to give to me.*

She went on to talk about how meaningful simple things like this were for her in terms of offering inspiration, and she would collect her own little message cards as a means of self–motivation for getting well.

Although Alexine did not confide in a lot of her friends about her illness, she did speak a bit about it to some. She recounts her experience in telling one friend:

> *I told a friend that I was going to see a psychiatrist and they said, whoa, really? You seem so happy and together! And I said, well, I am happy and most of me is together, but that doesn't mean I don't have problems, you know? It's normal.*

She often had the experience of others asking her why she needed to talk to a psychiatrist versus just a friend or family member. This eventually deterred her from confiding in people other than her family and mental health professionals.

In contrast to the reaction Alexine received from the friend described in the above quote, she recalls a more positive reaction from her very best friend. She described this friend as quite sociable, as someone who was always dragging her to parties, and various social events. Even though this friend did not fully understand the details of her eating disorder, she recalls her being aware of some problems early on. In response to this, her friend did try to help her as much as possible:

> *She noticed me going downhill and she was really trying to help me, but I think that when I was really on the cusp and just about to go into hospital, nobody really knew...she was supportive and everything, and she was always really outgoing and would just drag me out, and I'd end up feeling better when she did that, but she really didn't know that I was going to end up in hospital.*

When she finally did end up in hospital she recalls three other close friends telling her they had seen it coming:

> *But then the funny thing is that when I was in the hospital, three of my good friends said that they could see it coming. I say I underplayed it, but maybe they saw more than I thought they did. They probably did see more than I thought they did because I thought I was pretty good at being secretive and pulling away when I had my own troubles, but I guess what I thought they saw and what they really did was different.*

CHAPTER 9

DISCUSSION

The primary purpose of this study was to gain a better understanding of the experience of diagnoses and treatment of a mental illness. This was to occur for both researcher and participants. As discussed earlier in the methodology section, the "life world" or "world of daily living" concept, refers to an "intersubjective world" that describes and defines lived human experiences exactly as experienced (Wagner, 1970). He believed that "...the content and sequence of [individuals] experiences are unique and that...no two persons could possibly experience the same situation in the same way" (Wagner, p. 15). Given Schutz's phenomenological philosophy in understanding lived human experiences, I believed that a phenomenological approach was suited to this study. The in-depth individual interviews allowed each participant to dialogue and describe the uniqueness of their personal experience with a mental illness.

The meaning that participants' constructed from their experience with a mental illness was also a focus in this study. In speaking to the ways meaning is constructed within phenomenological philosophy, Schutz states that "acts of reflective attention" are a "...major importance in the study of meaning" (Wagner, 1970, p. 63). He believed that only a past event experienced is thought to be meaningful, or that "...only the already experienced is meaningful, not that which is being experienced." (p. 63). In the current study participants talked about their mental illness as experienced in the past. This reflective approach in speaking about their illness helped construct meaning for their experience as already lived.

Participants identified a number of themes in reflecting on the impact and meaning of their mental illness: stigma; self-concept/ identity, losses and frustration; isolation, and relationship dynamics. Lastly, each participant discussed personal insights and awareness gained as a result of their participation in this study.

The literature reveals that mental illness, in the form of depressive symptomatology, is a common psychological disturbance experienced in youth and adult populations (Beck, 1976; Kandel & Watson, 1988), and that the past decade has witnessed an increase in the identification of adolescent depressive symptoms and suicide (Dr. V. Kusumakar, personal communication, October 21, 1998). The impact of a mental illness on individuals' personal and professional lives is also documented. Poor academic performance, impaired interpersonal relations, impaired social functioning, and difficulties with family relations are associated problems observed in adolescent mental illness (Barnett & Gotlib, 1988; Harrington et al., 1990; Kandel & Davies, 1986; Kutcher & Marton, 1989; Pinto & Whisman, 1996; Stein et al., 1982). In discussing the experience and meaning of a mental illness, each participant experienced problems in one or another of these areas.

Self-Concept

Hughes and Brand (1993) speak about adolescence as a period of identity formation in pursuit of understanding their place in the world, questioning who they are and how they fit into their world. This is considered a major developmental task for adolescence, described as a transitional period for adolescence that can result in much ambivalence and uncertainty about their role and place in society. In speaking to the subject of identity formation and role identification, it is interesting how much each participant associated their self-concept and identity with their illness. John stated that:

> *In a general way, its sort of defined, ah, my being in a way since I was young...the people I know and the way that I think has been molded somewhat by the experience that I have had with the mental illness system, and with my own sort of trials with my illness itself. It had definitely had an effect on the way that I think and the way that I act.*

When Peter was first diagnosed he recalls feeling very low in self-esteem; feeling weak, worthless and as if he was not going to make it in life. When his depression was at its worst, he recalls feeling like a different person undergoing a major personality change whereby he lost complete interest in things he once enjoyed. His negative, or self-critical evaluation of himself at the time of his illness is a common psychological disturbance associated with a mental illness in youth, particularly in cases of depressive symptomatology (Beck, 1976; Kandel & Watson, 1988).

Although Alexine believed that her illness was very much separate from her person, she also believed that it was intertwined with her personality. She described her eating disorder thoughts and habits as being "chipped into her brain," making it difficult to separate herself from them. Eventually, she became aware of how much time and energy her illness consumed and eventually began the process of asking her self, "what am I doing? Is this all I am doing." From a phenomenological perspective, she was attempting to "...understand what it means to be who [she is] in the world..." wishing to become someone, or something other than her eating disorder. Wanting to separate from her illness and be the interesting person she believes she can be is also congruent with the philosophy of phenomenology in which a person aims for "fulfillment of [their] human nature so they can become fully who they are" (Van Manen, 1990, p. 12).

Stigma

Initially, all participants expressed difficulties with their diagnostic label, expressing concern about the stigma associated with the diagnoses of a mental illness. Each believed others would judge them because of their illness. Consequently, participants remained protective and selective in sharing details about their illness.

John was very concerned that others would think he was messed up, which left him feeling quite bad about himself because he had no control over his OCD symptoms. This is similar to the negative, self-critical feelings Peter experienced in response to his illness. However, as cited in the literature, and stated above, this is a common psychological disturbance experienced in youth and adult populations (Beck, 1976; Kandel & Watson, 1988) in response to a mental illness diagnosis, particularly in the case of depression.

In speaking to the stigma associated with a mental illness, Peter states, "*Well, it was embarrassing...what others would think ...I wouldn't open up to others...they'd think 'what a weirdo...couldn't tell friends...I feared friends judging me, so I didn't really go into details with them.*"

Alexine was very concerned about her friends judging her, stating: "*They're going to laugh or they're going to think I am just weird.*"

Although each participant had difficulty with their mental illness label, eventually they were accepting, believing this to be necessary in receiving the help they needed. John believes that he would not have made progress towards wellness had he not received a diagnostic label. In his opinion, the label was necessary in order to receive the treatment needed to alleviate his symptoms of depression and panic disorder.

Although Peter had great difficulty in receiving a psychiatric diagnosis, even more problematic was the need to see a psychiatrist. He believed that he was as low as he could go mentally, and worried that maybe he was going crazy. He recalls feeling worst upon first receiving his diagnoses focusing on the stigma; however, he later changed his attitude towards both the stigma of a mental illness and the attention required by a psychiatrist. In asking Peter about the issues of stigma and treatment by a psychiatrist, he responded by saying: *"No stigma, that is what they (psychiatrists) are there for--trained to do what they do...I would tell people to go for help, that's what they are there for."*

Losses and Frustrations

There were many frustrations and losses experienced by participants as a result of their illness. Some specifically to do with each participant's symptom experience and others to do with the impact of their illness on their personal and professional lives.

Not feeling understood by family, friends, and mental health professionals were a common frustration for all participants. They had great difficulty in describing and explaining how they experienced their illness so others could understand and be of help to them.

John was particularly frustrated and irritated with the treatment he received as an adolescent and young adult, feeling he wasn't helped as much as he expected. He felt the psychiatrist spent more time talking at him, versus with him. He felt like they really didn't listen. Except for John's experience with his latest psychiatrist with whom he has a very good rapport, and who has helped him beyond expectation, he experienced a similar feeling of not being listened to by psychiatrists that treated him in hospital. However, he feels that the nurses in the hospital were quite responsible and responsive in listening to his concerns and queries related to his illness and treatment protocol.

John's experience in hospital was that the psychiatrists were more concerned with treatment regimes related to a medical model of practice focusing on symptoms rather than exploring underlying psychological issues. He states, "*But what can happen I guess is that they get into routine about...they are not looking for other avenues of, or maybe more appropriate avenues of trying to treat the problem.*"

John's experience with the medical model's focus on symptoms in treatment of mental illness is congruent with the literature. Within the medical model, the phenomenology of adolescent mental illness has focused mainly on clinical characteristics, epidemiology, comorbidity, and treatment factors (Carlson, 1981; Geller & Luby, 1997; Hornstein & Putnam, 1992; Lewinsohn et al., 1995; Riddle et al., 1990) often attributed to biological and genetic factors (Duman et al., 1997).

Peter's most frustrating experience (with depression) was the fact that it took so long to completely recover. Otherwise, he had complete confidence and respect for the treatment he received from his psychiatrist. Aside from his initial difficulty with the stigma of his diagnoses, his experience in treatment was positive, he experienced very few frustrations except for the time that it took to completely recover from his illness.

When in hospital, Alexine experienced frustration with the medical staff and her treatment protocol. Sometimes she felt that the staff were more focused on getting her to eat and gain weight than talking about underlying issues related to her illness.

She believed the treatment protocol was more to satisfy the staff than to treat her illness, and was inappropriate and unhelpful in gaining an understanding of the origins of her illness.

When John was quite ill, he experienced decreased concentration, memory function, and cognitive abilities, causing him a great deal of frustration. He believes a combination of his illness symptoms and the treatment he received in the form of medications and ECT served to limit his cognitive abilities. Even more frustrating was losing his ability to perform his teaching responsibilities as a school teacher during the period of his illness. In speaking of his feelings of loss and frustration with having to leave work he states:

> *Very frustrating, being a teacher, I guess it was part of my personality I like to read, I think about things, and I like to think of myself as a fairly bright individual at most times, but not being able to have that function...it sometimes becomes very, very frustrating.*

One of Peter's frustrations was trying to understand and figure out what was wrong with him, and why he was experiencing the symptoms he did. He struggled in both accepting and talking about his illness with others, feeling they would not understand, or be able to help. Another frustration was not getting better as fast as he wanted. He recalls it took almost a year before he was completely recovered from his illness.

Also frustrating for Peter was his loss of interest, and abilities in academic performance. Due to the intensity of his symptoms, he was unable to concentrate sufficiently to complete academic assignments, and consequently reported failing grades in his first year of school. Decreased academic performance is a common occurrence in those experiencing a mental illness (Barnett & Gotlib, 1988; Harrington et al., 1990; Kandel & Davies, 1986; Kutcher & Marton, 1989; Pinto & Whisman, 1996; Stein et al., 1982).

Alexine's greatest frustration was her realization of the time and energy her eating disorder consumed. She felt this took away from personal and social activities. The negative impact of a mental illness on interpersonal and social relations, affecting one's interest and ability to properly function in social situations, is supported by the literature (Barnett & Gotlib, 1988; Harrington et al., 1990; Kandel and Davies, 1986; Kutcher and Marton, 1989; Pinto and Whisman, 1996; Stein et al., 1982).

Alexine also experienced frustration in not being understood, or others not understanding her illness. She felt others often misunderstood, or misinterpreted her symptoms. She spoke about others' belief that she was trying to control them with her eating disorder symptoms, which she presently denies.

Relationships and Isolation

All participants experienced a sense of isolation and relationship difficulties as a result of their illness. John recalls feeling quite distressed by his OCD symptoms as a child, which caused him to withdraw from others. He also spoke about the toll his illness had taken on his family. John expressed concerns about the impact of his illness on his son, worrying that it would negatively affect their relationship. Part of this has to do with the genetic vulnerability, or precursors of mental illness. Some of his concern is legitimated by the medical model's claim that mental illness is often attributed to biological and genetic factors (Duman et al., 1997) predisposing family members to mental illness symptoms in the future.

In terms of John's personal relationships, he acknowledges the negative impact of his illness on his interest and ability to socialize and interact with others effectively. Consequently, he often avoided large crowds, preferring the company of small groups typically including family and friends. However, as an adolescent, he often resorted to drugs and alcohol as a means to deal with his discomfort in crowds.

Related to John's experience, it is documented that substance abuse is another difficulty associated with mental illness, particularly in the case of depressive symptomatology (Kutcher & Marton, 1989; Pinto & Whisman, 1996). Nevertheless, it is important to mention that John believed his personality was that of a loner, and thus his discomfort in crowds is not to be pathologized, or considered an absolute symptom of his illness.

Peter also recalls isolating himself more from family and friends when he was ill. He denied having any interest, motivation, or time for people. In fact, he began to resent any interest or attention from others, feeling he neither deserved nor wanted it. He recalls having to break up with a girlfriend at the time of his illness and believes his depression was partly to blame.

As Alexine's eating disorder worsened, she reported difficulties in socializing with others. Since her biggest fear was eating and gaining weight, she avoided situations that might involve eating. Consequently, she missed out on parties, movies, and special dinners, increasing her sense of loneliness and isolation from others.

She recalls experiencing some relationship difficulties with her family, especially with her mother. She feels that had to do with her illness and how it expressed itself in her relationships. Since she often felt misunderstood by her mother they would frequently argue.

The literature supports the detrimental consequences of a mental illness on interpersonal relations (Barnett & Gotlib, 1988; Harrington et al., 1990; Kandel & Davies, 1986; Kutcher & Marton, 1989; Pinto & Whisman, 1996; Stein et al., 1982). Relationship difficulties in the form of conflict, misunderstandings, isolation, frustrations and sometimes separation were common experiences for research participants during the course of their illness.

Fears

Fear was another major issue for participants. One fear already discussed was the stigma associated with a mental illness. Initially, this was a strong fear for all participants. However, this lessened during the treatment phase of their illness.

In the beginning stages of illness, each participant expressed fear regarding his or her psychiatric symptoms. Because their symptoms had not yet been defined or named, they did know what was wrong, fearing something terrible was happening to them. This was particularly true for John and Peter in their panic attacks. Neither knew what it was, or why they were having this experience, which further increased their sense of fear.

Each participant feared losing control, or not having control over their illness. This was particularly true for Alexine with her eating and weight issues. She felt as if she had to "control, control, and control" in order to avoid gaining weight. Although she has better control over her irrational thoughts regarding this, she still struggles with the fear of losing control of her eating and becoming obese from the least bit of food.

Another significant fear expressed by participants was the fear of relapse. This was especially true for John who has had relapses in the past with his depressive episodes, one of which occurred during the course of this study. Peter also expressed concern about this, since his psychiatrist warned him of the possibility of a recurrent depressive episode in the future. Both John and Peter's fear of relapse is legitimized by the fact that experience with a mental illness in the past, particularly with depression, is a risk factor for the development and chronicity of future depressive disorders or future mental illness episodes (Harrington et al., 1990; Stein et al., 1982).

Insights and Awareness

As mentioned previously, the current study employed a semi-structured "life-world" in-depth interview format to investigate participants' lived experience with a mental illness. Kvale (1996) describes the "life world" as it pertains to phenomenological research and in-depth interviewing as "... the everyday lived world of the interviewee and his or her relations to it" (p. 30). As stated in the introduction of this thesis, the purpose of the "life-world" concept and in-depth interview method for the current study was to "describe and understand" (1996, pp. 5-6) participant's experience of diagnoses and treatment with a mental illness.

As a result of the interview process, participants believed that they gained more insight and awareness regarding the impact of their illness, and how much it affected their lives in general. In relating their insights, participants identified a number of themes, including self- concept/identity, stigma, fears, losses, and frustrations. As stated earlier, the impact of illness on relationship dynamics was also a major theme in participants' experience.

What benefits did participants gain from inclusion in the current study? As stated in the purpose of this study, the practical significance expected for each participant in the current study was that something positive would come from his or her participation. That the sharing of their "personal [stories] and interpretations of mental illness may lead to new and helpful insights such as ...hope, increased awareness, ... insight, a sense of liberation, [or a] certain thoughtfulness..." (Van Manen, 1990, p. 162). Evident in participants' data presentation, I believe this occurred for each participant.

Participants spoke of coming to gain a better understanding of their illness, which served to help them in their recovery process. Although neither John nor Alexine were fully recovered from their illness at the end of the research interviews, they nonetheless believed that the interviews helped them to redefine their goals and needs in terms of what they needed to do too fully recover.

John believed the interviews gave him the opportunity to discuss both the good and bad memories of his youth. This provided a vehicle to revisit those times in his mind, allowing for reflective thought that he now attributes as one factor in resolving some of his issues. Although he expressed some difficulties with the emotions stirred up by the interviews, he believed he benefited from having the opportunity to reflect on things he hadn't thought about for a long time.

Peter's appreciation of how much everyone cared and wanted to helped him in the recovery process was the most important benefit derived from his participation in the current study:

> *When I was finally healed, I guess I had no idea, but nothing was brought to my attention to full appreciate them, but now with these interviews I can look back and say, wow, they really tried hard, I can see that. They wanted me to get better.*

Peter believed there was great benefit in talking about his mental illness experience. The interviews allowed him to get his feelings out, helping him to better understand his experience enabling him to better help himself. He believed the insights gained from the interviews might help in preventing future episodes of depression and panic attacks because he now knew the signs of illness, and where to get help. He also believed that the knowledge and insights, gained through his own experience with depression and panic attacks, might allow him to help someone else sometime in the future.

Peter felt that the interview process was therapeutic. He believed that it gave him a chance to reflect back on his mental illness experience, and provided him with an opportunity to realize how far he has come. He described this as an unloading of everything and a weight taken off his shoulders, commenting on how helpful the interviews were and how much he actually enjoyed doing them.

Alexine believed that the interview process was helpful to her in many ways, resulting in insights and awareness absent before her participation in this study. She talked about how much the interviews legitimized her experience with anorexia. She expressed the difficulties she experienced in talking to friends and family about her mental illness, and how beneficial and easy it was to talk in the interviews since they were just for her: *"This is my experience, my story, sort of like feeling like I've finished my autobiography."*

Alexine expressed a feeling of reciprocity in the interview process. In a laughing tone she remarked "*it's not just me helping you with your thesis.*" Her feeling is evident in the following passage: "*Offering some of your own feedback, about your own background, that was nice...helpful, good for me to hear.*"

In summary, I believe the thesis claim that the participants would benefit from reflecting and talking about their experience with a mental illness was accomplished. Congruent with the concept of "life- world", and in-depth interviewing as it pertains to phenomenological research, I believe the current study allowed each participant "...to describe and understand their 'life-world' within the context of their mental illnesses" (Kvale, 1996, pp. 5-6). Participants' personal stories, descriptions, and interpretations of their mental illnesses provided meaning, insights, and increased awareness not present prior to their research participation.

Implications for Counselling

The research interview has been described as an interpersonal situation between two individuals who speak about a subject of mutual interest (Kvale, 1996, p. 125). In contrasting a research interview with a therapeutic interview, Kvale differentiates between the role of a therapist engaged in an interview with a client (or patient) and the role a researcher interviewing research participants. The dialogue and content shared in a research interview should not be as personal as that of a therapeutic interview nor should it be as "anonymous" and impersonal as "survey-questionnaires" (Kvale, 1996, p. 125). A researcher must develop a trusting rapport with participants as a therapist would with a client, but in order to allow for the exchange of research data, he or she must avoid building a therapeutic alliance.

In conducting this research, balancing empathy with objectivity while interviewing research participants was the core of my experience. It has been said that the "personal frames who we are, how we see the world, and thus constitutes an important contextual framework for the work we do" (MacKinnon, personal communication, September 1998) and that "in research as in conversation we meet ourselves" (Morgan, 1983). I mention these two quotes to elucidate my experience as the investigator of this thesis.

At times, I struggled to balance, and separate, my role as researcher from that of therapist. This was a struggle for two specific reasons: 1) My professional role and practice as a clinical psychiatric nurse produced a tendency to want to slip into that role; 2) The personal and sensitive nature of the content shared by participants predisposed me to responding in a therapeutic role as I would with patients in practicing psychiatric nursing. Although the latter did not pose a problem, it was a concern that required constant alertness on my part.

Having talked about the importance of separating the role of a researcher conducting in-depth research interviews from that of a therapist engaged in therapeutic interviews, literature supporting a phenomenological approach in both the study and treatment of mental illnesses is documented in the literature. For example, Jaspers (1968) discusses the difference between the subjective and objective experience of "psychic events," claiming that the subjective experience of psychopathology is best studied by a phenomenological approach. He thinks of this as "...an approach which only wants to see, not to explain" (p. 1318).

In examining the phenomenology of psychopathology, Varghese (1988) investigates the efficacy of a phenomenological approach in psychotherapy. He concludes that a Husserlian phenomenological approach to psychopathology and psychotherapy allows for a phenomenological understanding of the essence of one's being and existence (p. 401). This is believed to occur as a result of the therapeutic relationship between a client and therapist in which the therapist remains opened-minded relinquishing "...preconceived ideological notions...by [getting into the patient's [mind], be where he is, and indeed share his paradigm" (p. 401).

The "corrective emotional experience" of psychotherapy that allows clients to experience themselves differently, resulting in therapeutic change, is a function of the therapist's ability to maintain this open, non-ideological frame of mind. Varghese states that "...change results not merely from experiencing anew but rather in the experience of error" (1988, p. 401). Since an individual goes to a therapist for help in resolving personal difficulties, it is necessary for the clients to be open and honest in articulating their issues. More importantly, clients need to be able to describe the personal issues causing them distress in a way that helps the therapist to understand and interpret their experience. In relation to counselling, I support a phenomenological approach as one alternative, and effective therapeutic strategy, that will enable clients to describe their problematic experiences in a way that is helpful to both the client and the therapist.

Understanding a client's experience as he, or she experiences it, can only enhance the therapeutic relationship, in which both the client, and the therapist work together toward effective therapeutic interventions to benefit the client. Consideration of the basic tenets of phenomenology as a research methodology discussed in chapter three, some of which have been mentioned by Varghese (1988), elucidates the value of applying this approach in a counseling relationship. Specific implications for adopting a phenomenological approach in counseling are discussed.

In an attempt to understand and help a client with personal difficulties, a therapist must first be open-minded in listening to the description and meaning a client attributes to his or her issues (Varghese, 1988). The therapist must relinquish judgments, or biases that may misrepresent a client's experience. As with a phenomenological researcher, a therapist must ask a client, "what is this or that kind of experience like?" (Van Manen, 1990, p. 9).

Phenomenological research purports that consciousness is the only path accessible to humans in order to be connected within their world (1990, p. 9). Within the therapeutic relationship, although a client's state of "consciousness" may be their first way of presenting their personal difficulties, therapists are often challenged to be attuned and responsive to clients' unconscious state of affairs. Thus, with respect to the counseling relationship, consciousness is not the only path for humans in connecting with their world. This is evident in the contribution made by traditional psychoanalytical therapy that acknowledges the importance of transference and unconscious operations within ones psyche (Greenspan, 1993, p. 233).

In phenomenological research, connecting with one's "essence" is believed to occur if it "...reawakens or shows us the lived quality and significance of the experience in a fuller or deeper manner" (Van Manen, 1990, p. 10). In counseling, a therapist helps the client to gain increased insight and awareness of their being, their essence, with respect to the personal difficulties that brings them to therapy. Attempting to understand whom the client is in their world, and in the context of their emotional and psychological distress, a therapist must give and receive meaning that helps provide clients with appropriate solutions to their problems. Furthermore, by providing clients with an opportunity to completely describe and explain his or her "essence" can be the first step in aiding counselors to know and understand how to be most help in a therapeutic relationship.

Another implication of counseling has to do with the therapeutic relationship itself. The therapeutic relationship includes a relationship between therapist and client in which both persons are considered to be equal participants. It is common knowledge, and my experience as a psychiatric nurse, that if either a client or therapist is not an active participant in a therapeutic relationship, no progress can or will occur.

In "*A New Approach to Women and Therapy*", Greenspan (1993) states that "therapy is always a relationship between two persons" whereby the input of both the client and therapist impact strongly on the therapeutic change, or outcome of therapy (p. 234). Who the therapist is as a person in the counselling relationship is as important as the therapeutic techniques she or he employs in their work. In fact, "the therapist's most essential tool is herself as a person" utilizing her personal skills to further the interest, motivation, and desired changes of her clients (Greenspan, 1993, p. 243).

Greenspan states "just as the dancer must develop her body, so the therapist must develop herself as a person who can be useful to others" (p. 234). She speaks against the traditional "expert-patient" model of therapy advocating for a more equalized relationship between "women working together" (p. 234). Although her principals of therapy come from a feminist model of therapy/counselling, I believe this equalized attitude in the relationship between a therapist and client is equally applicable to both genders, and to different models of therapy.

In relating this to phenomenological research, this would be similar to the concept of the "intersubjective" that appreciates the need for the "other" (e.g., the therapist and client) in forming a "dialogic relation" with the phenomenon [of study], thus...validating the phenomenon as described [by a participant] (Van Manen, 1990, p. 11). Thus, in the case of counseling, there must be a "dialogic relation" between therapist and client if the client's issues (e.g., phenomenon) are to be know, understood, and validated by the therapist in such a way that allows the client to benefit from therapy. Since both seeking and accepting professional counseling can be difficult for individuals, I believe therapists have a responsibility to both themselves, and their clients, in attending to the work to be done in a therapeutic context.

In summary, I would like to say something about what has brought me to this research that speaks further to the implications of a phenomenological approach in the practice of counselling. As previously mentioned, the "personal frames who we are, how we see the world, and thus constitutes an important contextual framework for the work we do" (MacKinnon, personal communication, September 1998). I believe my personal experience as a psychiatric nurse has framed who I am and my interest in a study of this nature. This personal experience, combined with the limited research in adopting a phenomenological methodology to investigate mental illness, became the impetus for my work here.

In working with a mental health population I discovered patients often had much to say about their experience with a psychiatric illness: how their lives were affected by their illness, both personally and professionally. This posed many challenges and difficulties for patients as they attempted to normalize their lives in the midst of a not–so–normal experience, living with a mental illness.

Although patients were open and willing to divulge the trials and tribulations associated with their illness, this was shared on an informal basis: the content shared was not necessarily included in the treatment process. This reality alerted me to the invaluable information patients had to offer about their experience with a mental illness. I had the idea that attention to this might prove beneficial to both patients and mental health practitioners: beneficial in the form of increased insights and awareness of the unique experiential aspects of a mental illness. I thought that research into the depth and essence of this phenomenon might contribute additional knowledge in both the diagnoses and treatment component of psychiatric illnesses resulting in improved care for patients/clients, or mental health consumers.

Consideration of the primary tenets of a feminist approach to therapy: an individual is considered an expert of their own experiences; discovery of one's own voice within a therapeutic relationship is empowering; responses to, and insights about one's therapeutic process has much to teach counselors/therapist about the dynamics of therapy and the therapeutic relationships; and patients insights about their therapeutic process provide a better understanding of the contributions of therapy and therapist bear similarities with a phenomenological ideology in human studies: maintaining the uniqueness of an individuals' experience as an essential component to understanding human phenomena (Greenspan, 1993, Laidlaw, Malmo, & Associates, 1990, p., xiv). Borrowing from a feminist and phenomenological ideology in the practice of counseling, I believe is both relevant and appropriate in assisting counselors to gain a better understanding of their client's experiences, and thus has much to offer the mental health field in terms of clinical practice.

In conclusion, presenting arguments for a phenomenological approach in the research of mental illness, this thesis argues for the utility of a phenomenological approach in the practice of counselling. Specific to this study, I propose a phenomenological approach in working with a mental health population at both the diagnostic and treatment level of care. I believe this approach could assist practitioners to better understand and respond to the "essence" of one's experiences, aiding in the diagnoses and treatment of psychiatric illnesses. After all, patient's experiences form the content in both the diagnoses and treatment process, providing clues and direction to better service their needs. Thus, the experiential components of an individual's mental illness should be included in the overall assessment and treatment plan as part of the therapeutic process.

Reflections on Methodology: Strengths

The open-ended, semi-structured interview style employed in this study allowed research participants to speak freely to their experience, resulting in rich and valuable data. The "participant developed" themes that evolved from the research interviews provide direction for issues of focus in future treatment and care of a mental health population. This format is congruent with qualitative research methods using a phenomenological framework in which a researcher discovers what emerges from the data rather than "pre-selecting aspects of desire" or "those he wishes to manipulate," or defining the phenomenon in terms of his manipulations (Giorgi, 1994).

For example, in the current study, participants identified a number of themes in discussing the personal and professional impact of their illness including stigma, fears, relationship difficulties, and poor work performance associated with their illness. These themes emerged directly from the information participants shared in the interview process. Allowing one to identify, and name their experiences in the process of a therapeutic relationship, provide counselors with an opportunity to attend and respond to their clients needs that is both helpful and meaningful.

An in-depth exploration of the "essence" of participants' experience proved beneficial in assisting participants to gain a better understanding of their illness and their treatment process. This provided an opportunity for each to reassess and redefine their goals in terms of future work, and prevention of future episodes of symptoms associated with a mental illness. For example, Alexine discovered that she has never dealt with the underlying issues related to her eating disorder, and that this is an area of interest in future work with her therapist. Peter attested to the therapeutic advantage of talking about his experience with depression and panic disorder from start to finish. He believes that the "talking about it" in its entity contributed to his overall understanding of his illness experience. He voiced his willingness to use talk therapy again should he ever become mentally ill in the future.

This study offers an alternative approach to the diagnoses and treatment of a mental illness in a youth population that, to date, has received minimal attention. Because the phenomenological approach applied in this study proved to be a positive experience for research participants, it might have similar benefits in treatment of other individuals suffering from a psychiatric illness. Since feminist theory of therapy bears similarities with phenomenology in honoring an individuals' experience, I suggest that a phenomenological approach might be useful in a counseling/therapeutic relationship, just as feminist therapy is useful in a therapeutic relationship.

Limitations and Recommendations

Although not a limitation, it is important to note that results from this study cannot be generalized to any other population other than to the three identified participants. It would be interesting to conduct a similar study with a larger population in making a comparison and/or contrast between participants. Considering the volume of data produced by this study, with the inclusion of only three participants, I suggest the need for modification in the methodology and/or methods in future studies including a large population sample. I would even suggest methodological changes in future studies with a small population utilizing in-depth interviews as a method of study. I recommend this because of the size of data produced in the current study that required a lot of time and effort to analyze.

One suggestion to limiting data size for future studies of this nature, is substitution of a semi-structured open-ended interview format for a more structured format. In the current study, the interview questions were so open–ended that digressions sometimes occurred. This resulted in irrelevant and unusable data for the purpose of the thesis. Yet these data still required reviews and consideration before discounting its potential use in data presentation, resulting in a labor-intensive exercise. Nevertheless, I caution against a complete structured interview using a phenomenological methodology, as this may sacrifice the quality and purpose of a phenomenological research approach: to explore the essence of individuals' experiences in an open and non-restricting manner.

Another recommendation to accommodate a larger population sample or management of large data sets is to apply additional control variables for participant inclusion. In this study, participant criteria were few: presence of a psychiatric illness; contact with a psychiatrist; outpatient, or post-acute status; and absence of active psychotic, suicidal, or acute depressive symtomatology. Although all these variables should be included in future studies in participant selection, I recommend the need and control of additional participant criteria as one method in data condensation.

For example, selecting participants with a single diagnosis illness is one suggestion in condensing data size in future studies. However, it is important to note that most individuals diagnosed with a psychiatric illness typically have co-morbidity diagnoses, or dual diagnoses, and this may be difficult to fulfil as a criterion variable.

A more effective and realistic recommendation in selecting appropriate participant criteria is to control for length of time with illness. In this study, the length of illness varied for each participant. Thus, the size of data varied with each, some producing large quantities of data and others smaller quantities. More specifically, I suggest a limit of one to two years from time of diagnosis to time of participation. This was the case for one participant, Peter, who was ill for one year. Data produced from Peter's interviews was half the size of the other two participants, and thus more manageable to analyze.

One last consideration recommended for research utilizing a phenomenological methodology, and an in-depth interview method, is the application of a qualitative statistical program in performing data analyses. A manual coding procedure analyzed the data from the current study, which required numerous hours of work. I suggest the application of analyses programs such as Altalis/TI, NUD-IST., or Ethonograph in future studies which will be generating interview related data.

CHAPTER 10

INTERVIEW PROCESS

The methodology framework in the current study, phenomenology and hermeneutics, are important concepts in the discussion of participant's reflective thoughts in living with a mental illness. Briefly stated, phenomenological hermeneutic research concerns itself with "...lived experiences" as experienced by persons (Van Manen, 1990, p. 9) in which meaning can be derived through "acts of reflective attention" (Wagner, 1970, p. 63). This provides an opportunity to examine the depth of the experience under investigation. Also important to the research methodology is the definition of "experience" and "meaning" in accordance with a phenomenological framework. Review of the definitions of these terms, as they relate to phenomenological research, was discussed earlier in the methodology section (pp. 17-18).

Schutz's (Wagner, 1970) phenomenological framework for understanding lived human experiences, lets us examine participants' reflective thoughts concerning his or her mental illness in an effort to gain a better sense of this phenomenon. An understanding of the meaning and the impact of a mental illness for research participants are spoken to in their personal reflections.

Participant's Personal Reflections

A semi-structured "life world" in-depth interview employed in this study describes the "life world" as it pertains to phenomenological research and in-depth interviewing as "... the everyday lived world of the interviewee and his or her relation to it" (Kvale, 1996, p. 30). This type of interview "...is defined as an interview whose purpose is to obtain descriptions of the life world of the interviewee with respect to interpreting the meaning of the described phenomena" (1996, p. 5-6). Relevant to the current study, the purpose of a "life world" concept with an in-depth interview method "describes and understands" participants' experience of diagnosis and treatment with a mental illness (p. 29).

Reflecting back to the purpose of this thesis, to investigate and describe the phenomenological experiences of participants who have been diagnosed and treated with a mental illness, suggests a practical significance. The practical significance expected for each participant was that something positive would come from his or her participation. It was hoped that sharing of "...[their] personal [stories] and interpretations of mental illness may lead to new and helpful insights such as "...hope, increased awareness, ...insight, a sense of liberation, [or a] certain thoughtfulness..." (Van Manen, 1990, p. 162).

Following the completion of data collection, I felt a sense of in-completion. Some afterthoughts revealed the fact and necessity that each participant should have an opportunity to provide feedback about the experience of going through the interview process. My question, "how can I verify the practical significance of the study: to benefit participants in a positive manner--without investigating the effects of the interview process?"

The following descriptions and verbatim quotes elucidate the interview process as experienced by each participant. My findings are categorized with the follows subtitles: Preconceptions; Experience in Beginning the Interviews; Reactions from Others; and Personal Benefits, all derived from the interview process.

Preconceptions

Two research participants, Peter and Alexine, discuss their preconceptions of the interview process prior to their participation. Peter's initial reaction to recruitment into the study by his psychiatrist was:

> *Well, he (psychiatrist) called me on my parent's 25th wedding anniversary and there was about 100 people at my house, and he called, and asked me if I wanted to do these interviews. And I said, without a doubt, I didn't hesitate. I just said yes right away. Cause I had no fear of it (depression) coming back and obviously he didn't, or else he wouldn't have called.*

Peter expressed complete comfort and sense of control, experiencing no fears or worries about negative effects from his participation. He did express a concern about stepping on the wrong toes: "*I was worried about stepping on the wrong toes... I had some reservation about that, but I just thought about that on your part.*" Peter wasn't exactly sure what I wanted, but saw the interviews as an opportunity to help someone: "*So if I can help, like the cliché, if I can just help one person.*"

In describing her preconceptions of the interview process, Alexine envisioned a pre-structured format with specific questions. She felt it might be difficult to answer open-ended questions because of her tendency to go off on tangents, afraid she would not answer the questions adequately. Alexine, like Peter, wondered and worried about giving the researcher what was needed stating, "*I was worried a bit. 'Am I going to give what you need?' But it came to me just getting stuff out--wondered if I would give what you want in comparison to other participants.*"

Prior to starting the interviews, Alexine envisioned herself as a subject of the kind of exploratory experiment a medical student might do on pigs, or something of that nature. This preconception created feelings of vulnerability for her. She expressed great relief in learning of the study's semi-structured interview method.

She expressed concerns about having something to say in the interviews. She attributes this to her ongoing tendency to minimize her illness. She never completely accepted that she was diagnosed with anorexia nervosa, and she often rejected the phrase "anorexia nervosa," referring to her mental illness as "my problems", or "my irrational thoughts." However, she believes that the interviews helped to legitimize her illness, stating, *"I am being interviewed for the real thing."*

She said that not talking about it in an experiential manner allowed her to deny the reality of her illness. She spoke about how the mind can play tricks on one, and that the interviews helped her to realize that her thinking processes had not changed much since the acute stage of her illness. She felt the interviews helped her realize how much the eating disorder experience was a part of her, and will always be with her.

Alexine also worried that she might be intimidated, because she believed she would be the only one sharing:

> *I thought it would be intimidating because it would just be me sharing and I would feel kind of vulnerable in a way-- right-- that's what I pictured. I didn't have any qualms or problems doing it-- thought that would be fine, but I thought I would kind of feel vulnerable sharing this with somebody I didn't know, but I didn't feel that way at all.*

Alexine was flattered by her psychiatrist's encouragement to act as a participate in this study:

> *It was nice to hear I would be a good candidate. My psychiatrist thought I could handle it and that I am articulate and would be a good person for the study. That stuck with me. I found that really flattering, after all, my psychiatrist heard all the irrational things I have had to say--see me through the whole thing, and I still have my head half screwed on, hey, maybe I don't look so strange from the outside (in a laughing tone).*

Beginning Interviews

Participants shared a range of thoughts and feelings about beginning the interview process. Starting with Alexine, she believed there was some unexpressed, or mysterious purpose to the study that was intentionally hidden from her, and subsequently felt the need to figure this out. She says:

> *When beginning the interviews, I wasn't sure where you were headed-- like with all your interviews, if you were trying to get one thing-one theme; but I was curious too- just wanted to see if I could figure out what it was. After the first couple--maybe even after the second one-- said you didn't really have one theme. Than I thought you were trying to trick me (laughs). Seriously, because I thought you had other people to interview, that you were just trying to see if there was a common link, you know-- so then, I was wondering if...so then I think, isn't that great- just research for research sake.*

Alexine described the semi-structured in-depth interview method as a form of dialoguing, as opposed to structured, or straightforward type of questions. She was able to talk about her mental illness experience in an open manner that allowed her to move easily into other topics. She reported having this nice feeling at the start of the interviews. She often wondered what she would say in the next interview and what questions she might ask. Nevertheless, there were difficult times for her with the interview process. For example, she was at a loss for words about such things as the origins of her illness. In spite of her hesitations, Alexine found it helpful to think about things discussed within the interviews, stating that the interviewer, and the process itself, offered interesting feedback.

Peter expressed complete comfort in doing the interviews. He trusted both the interview process, and me as the interviewer, believing no harm would come from his participation. His comfort and fearlessness regarding the process is evident in his own words: "*I really wanted to do the interviews, I knew there was nothing to be concerned about, like I told you. From day one, there was nothing that could happen to me.*" Peter perceived my role as one of listener, as someone who would just sit and listen to him in a non-threatening way. He denied this as being a precarious situation for him.

Reactions: Others

Peter was the only one whose participation elicited negative reactions from others. Initially, his family tried to stop him, fearing that the interviews might trigger another depressive episode, or panic attack. Especially with the knowledge of the potential for a relapse of symptoms as communicated by Peter's psychiatrist. He recalls a female colleague expressing concern, and questioning the safety and benefits of his participation:

> *When I told a lady at work--cause they all knew what happened to me, I had mentioned it in the past-- and I told a lady at work and she described it as just talking about a person's death the entire time.*

Peter's family and close friends also worried that the interviews might cause another depressive episode. Peter recalls them expressing their concerns many times following the interview sessions:

> *They would look at me in a funny way asking if I was alright? The first question they would ask me when I'd come through the door would be, "how are you doing today?" I'd say, I'm all right." I'd just be sitting there and they'd all be looking at me like I had ten heads, or something like that.*

Peter goes on to say how he wanted to have fun with their reactions, and tease them in some way, but declined thinking this would be cruel and further fuel their already concerned minds.

In spite of other's concern, Peter remained adamant in his decision to participate in the interview process. He opine that his mental illness experience will always be with him and believed talking about it would be of benefit to him, and maybe to others in the future. He states: "*It will always be with me and why shouldn't I take it-- and put it to work and receive some benefit out of it, whether it be for health care, or other patients or whatever.*"

He believed that if he just put it behind him, it would never be brought out in the open and talked about. Having received psychiatric treatment for one year, and having recovered from his illness, Peter felt ready to talk about his experience stating, "*I was ready to look back on it when I was done with Dr. ZZ. I didn't not want to talk about it!*"

Benefits

All participants believed themselves to have benefited from their participation in the interview process, gaining insight, and increased awareness. The following quote best summarizes John's experience in participating in the research interviews.

> *It's been a positive thing overall. I was talking about this with my wife, ah, over the week-end, and she knew we were going to have this session in the morning, um, and overall it has been a fairly positive experience for me because it has given me the time to talk about some of the things, ah, that have gone on, and has had some therapeutic value in that respect...It has been interesting to go sort of through the time line and it's something that has made me think more about the different stages of my life.*

The interviews gave him the opportunity to discuss both the good and bad memories of his youth. This provided John with a vehicle to revisit those times and provoked reflection, helping him to resolve some of his personal issues.

John believes that the difficult emotions raised during the interviews served to further his work with both his psychiatrist and psychologist. Although he encountered some negative thoughts and feelings following some of the interview sessions, overall it was a positive experience for him:

> *Its been worth while to reflect back on [my experiences] and it's been good to sort of talk about more recent times as well because when we were going through the different stages and different aspects of my experiences, it helped me to sort of put things into a context. Put things into a time and place. Being able to reflect on things has helped me to remember some things and its not always when we are*

> *doing the sessions, but sometimes days later, or even weeks later. I will be thinking about something that we may have talked about, or may have talked about with some other professional, ah, things, connections start to be a little more so. It helps me make connections and it has been therapeutic in that way.*

Peter's first revelation in terms of interview benefits, was how much his family, friends, and psychiatrist had helped in his journey from illness to wellness, stating:

> *When I was finally healed, I guess I had no idea, but nothing was brought to my attention to full appreciate them, but now with these interviews I can look back and say, wow, they really tried hard, I can see that. They wanted me to get better.*

He spoke of his need to talk about his mental illness after recovery. He believes this enabled him to better understand himself, and that the knowledge and insights gained through this experience, might better prepare, or prevent a future episode of depression, or panic attacks. He also believed that the knowledge and insights gained from his experience might enable him to help someone in the future suffering a similar disease.

Peter also found the interview process to be therapeutic, giving him a chance to reflect back on his mental illness experience:

> *A chance to go from start to finish of the entire two and half years-- just to get it all out there and talk about the entire thing. Because I've never really talked about the entire thing from start to finish, right! I've always talked about bits and pieces, how I was, now I'm better, so let's move on. But now, with these interviews, I got to talk about the entire thing.*

He described this as an unloading of everything, and a weight taken off his shoulders. He commented on how helpful the interviews were, and how much he enjoyed doing them.

He believes that the interview process provided an opportunity for him to see how far he has come in terms of his recovery:

> *Yeah, like over the two days last week, I went home and just shook my head. I couldn't believe it. I didn't know myself back then when I was suffering from depression, and to see myself now, and just look back at everything I've done, and how far I've have come.*

Alexine believed that the interview process was helpful to her in many ways. It provided new awareness and an opportunity to talk. She talked about how much the interviews legitimized things for her. She spoke of the difficulties she experienced previously in talking to family and friends about her mental illness, and how beneficial and easy it was to talk in the interviews since they were just for her:

> *This is my experience, my story, sort of like feeling like I've finished my autobiography. Initially, I didn't know where I was going to start, but than it kind of came all around into a nice little package. Feel like I've gotten it all out, didn't leave anything out--got a lot off my chest--cleared up a lot of things--came around into a nice little package.*

Alexine expressed a feeling of reciprocity in participating in the research interviews. In a laughing tone she remarked, *"it's not just me helping you with your thesis."* Although she did not always have the answers, some of the questions and feedback were profound and thought provoking:

> *Offering some of your own feedback, about your own background, that was nice...helpful, good for me to hear. Maybe that is why I initially thought the interviews would be intimating, because I thought it would be just me sharing and*

I would feel kind of vulnerable in a way--right, that is what I pictured, like I didn't have any qualms, or problems about doing it--thought that would be fine, but thought I would kind of feel vulnerable sharing this with somebody I didn't know. I didn't feel that way at all.

The only doubt Alexine expressed early in the interview stage was her uncertainty about my real goal or purpose in the study. Her thoughts on this matter are expressed an in earlier quote found in the middle of page 181.

Interview Structure

To close the discussion on the interview process, I asked each participant to make a few brief statements about the specific interview method (i.e., semi-structured) employed in the current study. They offered the following comments.

John: The open-ended style made it easier to talk.

Peter: I felt this has been very well organized. Well done!

Alexine: Being able to talk openly, like a discussion, dialogue, made it easier to talk.

John: Interview setting--very comfortable atmosphere.

Peter: It was very well put together--I would have conducted it the same way.

Alexine: Nice not to have to explain self so much in terms of "why's."

John: Felt you ran things smoothly. You informed me well.

Peter: Just had an open discussion. Worked for me. I wouldn't have changed a thing.

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APPENDIX A

Letter of Consent:

This study is in partial completion of the degree of Masters of education in counselling, Acadia University, Wolfville, Nova Scotia.

Purpose: The purpose of this study is to investigate and describe participant's experience with a mental illness as identified, diagnosed and treated by a formal psychiatric service. Identity, self-concept, personal development, life meaning and lifestyle changes are suggested topics in exploring this experience. The value in such a study is twofold: 1) That each participant will gain a deeper understanding and awareness of their experience which is of personal benefit and 2) That mental health researchers and practitioners will too enhance their awareness, thus their practice, in serving mental health consumers.

Participants: Individuals between 18 and 35 years of age diagnosed and treated with a psychiatric illness are welcomed. Participation criteria include informed consent, formal diagnoses by an official psychiatrist or mental health service, and absence of any acute psychotic, suicidal, or depressive symptomatology. Parental consent may be necessary for those under 19 years of age.

Method: Data will be collected and processed via in-depth tape-recorded interviews between principal investigator and one interviewee per interview. Time of interviews is expected to range from one and a half to two hour. Tape-recorded interviews will be heard and transcribed by an appropriate transcriber selected and approved by investigator, supervisor, and thesis committee member. No other persons will have privilege or access to tape-recorded interviews or transcriptions unless requested and authorized by participants. Interviews will be of a reflective and explorative nature between interviewer and interviewee. Three to four interview sessions over a one-month period conducted in a place mutually agreed upon by both participant and interviewer will occur. The audio-tape recorder will be stopped at any time during the interview when and if requested by participants.

Participation is completely voluntary in which case you may withdraw at any time without enduring any consequences. Information gleaned from this study will be held in the strictest confidence, knowable only to your self and investigator. Identity and self-identifying information will be protected as within the researchers' control ensuring anonymity. A fictitious name of your choice is suggested. Your approval will be requested before any excerpts (from interviews) are used in the final thesis to ensure accurate representation, documentation, and final approval. Additionally, data gathered from interviews (i.e., audio tape-recordings, transcriptions, logs and notes) will be used strictly for the purpose of this study only and disposed of upon completion of the study and degree program.

Ethical consideration: Based on the sensitive nature of the current study and the possible affective responses, it is suggested that all participants have available to them a support person or formal counselor.

Participant signature:________________________

Investigator signature:______________________

Date:__________

APPENDIX B

Interviews: Guiding Questions

Experience of Treatment and Diagnoses

- Tell me about how you felt upon first receiving a psychiatric diagnosis?
- How did others (i.e., family, friends, and significant other) react to you?
- Tell me if you felt treated differently by others as a result of your diagnosis?
- Tell me about how this may or may not have changed your life style?
- Overall, how has this experience been for you?

Contact with Mental Health System

- How did you come know or learn of your diagnosis?
- How was this communicated to you and by whom?
- Tell me about how you perceived being treated by your psychiatrist?
- Were there any differences in how you were treated depending on the mental health professional (i.e., nurses, psychiatrist)?
- Did you receive all the information you requested and wanted?
- Were you satisfied with what was provided to you?
- Tell me if you felt supported by psychiatric staff and how?
- Describe your feelings, thoughts, regarding the time and attention paid to you by staff?
- Overall, how would you describe your contact with mental health services?
- What have been the consequences, if any, of this experience?

APPENDIX C

Participant Demographic Sheet

Fictitious Name:________________________________

Age: _____________

Sex: ______________