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Voices of Mental Illness: Individual Experiences

by

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ABSTRACT

Although there has been much research in the area of medical treatment of mental illness, one area that has been neglected is the experiences of individuals with a mental illness. This study is a phenomenological exploration of the experiences of five individuals in regards to diagnosis, treatment, stigma, and recovery. The participants of this study were selected from a small city in central Alberta. In-depth, semi-structured interviews were conducted with five individuals diagnosed with a mental illness. Participants of this study indicated fears of hospitalization, positive and negative treatment experiences and impacts of diagnosis, restricted knowledge of recovery, and lack of diagnosis education.

For my family.

Your love inspires me.

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TABLE OF CONTENTS

CHAPTER ONE

INTRODUCTION

One of every five Canadians will be affected by mental illness during their lifetime (Canadian Mental Health Association, 2002). In fact, between the years 1999 and 2000, 171,577 Canadians were hospitalized in both general and psychiatric hospitals as a result of a mental illness (Statistics Canada, 2002). Therefore, mental illness represents the most costly health condition in Canada, with a reported $6.4 billion allocated yearly to treatment and services (Canadian Mental Health Association, 2002). However, despite the increasing numbers of individuals being affected by mental illness, there is relatively minimal research addressing the treatment experiences of these individuals.

Several aspects of mental health treatment have been identified as important. However the research in the area of mental illness largely consists of treatment-efficacy studies, with generally little attention focusing on treatment experiences and the impact of diagnosis on the individual. More recently, there has been a growing interest in the satisfaction of individuals accessing mental health services. Researchers have indicated that individuals have expressed various concerns with the current system, specifically with efforts of addressing stigma, isolation, and unemployment (Glass & Arnkoff, 2000). Other areas of concern include forced hospitalization, powerlessness in treatment planning, emphasis on lifelong medication compliance, and chronic disability (Coursey, Farrell, & Zahnister, 1991).

Recovery literature addresses misperceptions of mental illness and chronic disability, common themes, and experiences of individuals who engaged in the process(Anthony, 1993; Deegan, 1996; Lovejoy, 1984; Ridgway, 2001). Recovery entails the belief that individuals can grow beyond the limitations of their illness. The concept of growing beyond limitations may facilitate hope as the implications of recovery challenge the traditional medical view that an individual affected by mental illness must adjust to a lifetime of chronic disability. It also provides hope to individuals who are trying to lead meaningful lives in the community (Anthony, 1993).

The stigma associated with a mental illness diagnosis, including all of the negative connotations of a diagnostic label, may greatly affect the functioning and quality of life of individuals with mental illness (Thoits, 1985). Researchers have indicated that diagnosed individuals are generally aware of the negative societal stereotypes associated with a mental illness diagnosis. These may result in negative psychological impacts, such as the internalization of the psychiatric label (Hastorf & Isen, 1982). The process of internalizing may result in a self-fulfilling prophecy in which individuals align their self-concept to match societal stereotypes (Hastorf & Isen, 1982). The stigma resulting from a psychiatric diagnosis may also impact support systems because individuals may experience abandonment by families and friends and denial of services such as appropriate housing and employment (Leete, 1992; O'Reilley, 2001).

The purpose of this study is to learn from the treatment experiences of individuals affected by mental illness. For this reason, participants were asked about various issues relating to diagnosis, including the personal and social impact of a mental illness diagnosis, stigma, recovery, and diagnosis education.

Definition of Terms

For the purposes of this study, the following definitions are employed.

Mental illness: a condition that causes serious abnormality or disorder in a person's behavior or thinking capacity, irrespective of intelligence. *Mental illness* is a broad term that describes many conditions ranging from mild to severe. A mental illness can affect an individual's emotions, clarity of thought, concentration, and relationships with others. It is distinguished from a mental health problem by the severity, frequency, and duration of symptoms (Thompson, 1995, p. 852).

Stigma: a social phenomenon that involves at least two fundamental components: (a) recognition based on some distinguishing characteristic or "mark," and (b) a consequent devaluation of the person (Heatherton, Kleck, Hebl, & Hull, 2000).

Consumers: individuals with a mental illness diagnosis who access mental health services. The term *psychiatric survivor* is also commonly used (Bassman, 1997).

Recovery: a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and roles. It is a way of living a personally satisfying, hopeful, and contributing life, despite the limitations caused by a mental illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness (Anthony, 1993, p. 15).

Labeling: application of a name to a phenomenon or pattern of behavior. The label may acquire negative connotations or be applied erroneously to the person rather than to his or her behaviors (Durand & Barlow, 1997). Positive aspects of labeling include providing health status information and appropriate treatment as a result of diagnosis (Sattler, 2001).

Self-concept: one's self-identity, a schema consisting of an organized collection of beliefs and feelings about oneself (Baron & Byrne, 1997; Goldstein, 1994). Self-concept is a person's definition of who he or she is, including personal attributes and unique qualities. The self-concept is a special framework that influences how we process information about the social world around us and about ourselves. It includes the information and feelings relevant to our past, present, and future selves.

Significance of the Study

Researchers have generally overlooked the treatment experiences and the personal impacts that a mental illness diagnosis has on an individual. Typically, they have focused on treatment efficacy related to best practices in mental health. Until recently, exploring the experiences of individuals affected by mental illness has been overlooked in part because of the preferred research paradigm in the medical profession. During the 1990s, however, a shift occurred from treatment-efficacy studies to first-person accounts of treatment and recovery experiences.

The current study describes the literature identifying issues related to mental illness and in addition provides a medium through which affected individuals could voice their experiences and opinions. The research is intended to examine the strengths, weaknesses, and gaps in available services to better meet the needs of recipients of mental health services.

Purpose of the Study

This research project was intended to provide a medium through which to voice the experiences and opinions of individuals affected by mental illness because this type of research is largely absent from current literature in this area. The purpose is to explore the impact of a mental illness diagnosis on an individual, treatment experiences, and the adjustment process as an outpatient. More specifically, the research question was, "What are the experiences of individuals affected by mental illness?"

Order of Presentation

In Chapter Two, *Review of the Literature*, areas pertinent to the experiences of individuals affected by mental illness are reviewed. Specifically, a general history of the literature includes a discussion of recovery, stigma, labeling, and hospitalization experiences. Various aspects of the experiences by individuals affected by mental illness are addressed.

In Chapter Three, *Method*, qualitative inquiry and the phenomenological method utilized in this study are discussed, including interviewing, bracketing, participant selection, data collection and analysis.

In Chapter Four, *Introduction to the Participants*, a brief biographical summary for each participant involved in this study is presented. This study included two males and three females with a mental illness diagnosis.

In Chapter 5, *Results*, the common and diverse themes as a result of thorough analysis of participant interviews are identified and presented.

In Chapter Six, *Discussion and Conclusion*, a discussion and summary of the findings of this research are presented. The discussion includes an examination of the limitations of this study, implications of the findings, and future directions for research.

CHAPTER TWO

REVIEW OF THE LITERATURE

Labeling

Focus of Research

Until recently, the focus of research has concentrated on societal reactions to deviance instead of the meaning of a label as determined by the recipients of diagnostic labels (Weinstein, 1983). Although the amount of research in the area of stigma has increased, there has been relatively little research exploring how individuals affected by mental illness attempt to deal with the implications of their diagnostic label (Link, Cullen, Mirotznik, & Struening, 1992). Consequently, the reported effects of labeling may be more or less severe than actually experienced by affected individuals. Theories of labeling are briefly discussed because the impact of labeling is often related to diagnosis.

Theories of Labeling

The three theories briefly outlined here highlight different views of labeling and the possible impacts a diagnosis may have on an individual. Labeling theorists asserted that individuals exhibiting deviant behavior may be labeled with a mental illness and consequently experience rejection when attempts are made to resume normative roles. Consequently, labeled individuals are encouraged to fulfill the role of a mentally ill individual as a result of this rejection (Markowitz, 1998). Persons who are labeled are thought to structure their behavior in order to conform to expectations and cultural stereotypes of mental illness. Therefore chronic mental illness is seen as a role and psychiatric hospitals are viewed as reinforcement agencies of the very behavior they are assumed to correct. Once the individual has been labeled as 'crazy,' he or she is 'forced' to become a member of a deviant group of individuals. Subsequent hospitalizations are explained by the effects of social rejection rather than symptoms of mental illness (Weinstein, 1983).

Labeling theory is challenged by the theory of the self-fulfilling prophecy; specifically, that a mental illness diagnosis is followed by expectations of discrimination resulting in a negative, self-fulfilling prophecy. In an attempt to avoid rejection, the individual may withdraw and isolate him or herself. This may result in greater levels of stress and, consequently, exacerbated symptoms of mental illness. The cycle of expectation, stress, symptoms, labeling, and stigma results in the actualization of the prophecy (Markowitz, 1998). Overall, this theory is based on the assertion that expectations of rejection and stigma rather than actual experiences of rejection and stigma negatively impact an individual.

Another view supports a medical definition of mental illness in which the cause of mental illness is rooted in biological etiology and the condition is treated within the medical model. The psychiatric facility is a site in which the person is treated and shielded from environmental factors that may contribute to the presence of their symptoms (Weinstein, 1983). Therefore the psychiatric facility is viewed favorably and relapse is explained by re-exposure to factors that precipitated the initial episode (Weinstein, 1983). This theory posits the psychiatric facility in a positive manner in contrast to labeling theory. In addition, environmental factors are identified as impacting individuals in comparison to specifically identified societal rejection or anticipated stigma.

Stigma and Mental Illness

Some social scientists believe that stigma is an unimportant part of the lives of individuals affected by mental illness (Link et al., 1992). In a study by Link et al., members of the public were asked to evaluate vignettes (written or acted) in which conditions of labeling (former mental patients vs. no mention of mental illness) and behavior (normal vs. indicative of mental illness) were experimentally manipulated. The results indicated that the presence of abnormal behavior and a diagnosis of no mental illness was indicative of rejection. In addition, knowledge of an individual's psychiatric history seemed to have little impact on the responses of the participants. Last, Link et al. reported that surveys of the experiences of individuals affected by mental illness indicate that they are rarely able to specify instances of rejection. This research questions the severity and frequency of rejection and stigma experienced by individuals with a mental illness. However, it does not address the possible impact of the hypothetical nature of vignettes and the participants responding in a socially acceptable manner.

Stigma and Self-Concept

Stigma is often associated with a mental illness because psychiatric diagnoses have many negative connotations associated with them, such as 'insane' or 'crazy' (Thoits, 1985). Therefore an individual who suffers from mental illness is generally aware that the condition is undesirable (Conrad & Schneider, 1992). Researchers have suggested that negative psychological impacts such as internalization of a mental illness label occur in individuals as soon as first contact is made with the mental health system (Hatfield & Lefley, 1993).

Researchers have also indicated that labeled individuals seem to be attentive to information that confirms their diagnostic label versus information that challenges it. If the connotation of a mental illness label is 'crazy' as suggested by negative societal stereotypes, individuals may internalize that they are 'crazy' leading to a self-fulfilling prophecy. The internalization of stereotypes occurs as a result of replacing the element of 'self' as previously construed with the newly construed, more negative version of the 'self' (Kelly, 1955). The construing process allows individuals to align their self-concepts to match generally accepted stereotypes in society (Hastorf & Isen, 1982). Individuals attempt to maintain a positive self-concept; however, with increased contact with the mental health system their positive self-concept may be engulfed by the patient role. Role engulfment may occur due to the internalization of stereotypes, resulting in a more negative view of the self(Lally, 1989).

Being admitted/committed to a psychiatric facility seems to have the greatest impact on the patients' self-concept in comparison to outpatient community treatment. Individuals may try to maintain their self-concept by various techniques such as overemphasizing achievements or labeling their illness in a less damaging way such as "I am depressed and not schizophrenic" (Lally, 1989; Townsend &

Rakfeldt, 1985). These techniques seem to emphasize general awareness of the stigma attached to mental illness and the possible negative impacts associated with a psychiatric diagnosis such as discrimination and rejection (Townsend & Rakfeldt, 1985).

Community services have also been identified as having a negative impact on an individual. Townsend and Rakfeldt (1985) contended that admission to a psychiatric hospital would be more stigmatizing and produce more negative impacts on an individual than community treatment would. However, their participants indicated that even community treatment would be viewed negatively by others and would also negatively impact their self-concept (Townsend & Rakfeldt, 1985). These findings suggest that societal perceptions may impact a person's self-concept as well as potentially undermine attempts at recovery (Davidson & Strauss, 1992).

However, recent research has suggested that diagnosis, treatment, and hospitalization also have many positive impacts often not identified in previous literature (Anthony, 1993; Deegan, 1996; Jacobson, 2001; Ridgway, 2001). In a study by Ridgway, 25 recovery narratives were analyzed and one common theme was evident. These individuals were all working towards recovery after diagnosis and treatment. The reports identified the positive impacts of diagnosis and treatment such as reintegration into the workforce, management of symptoms, and enhanced daily functioning. This was also evident in published personal narratives by individuals diagnosed and treated for a mental illness (Anthony, 1993; Deegan, 1996; Jacobson, 2001; Lovejoy, 1984; Ridgway, 2001). Therefore, despite previous literature that generally emphasized the negative aspects of treatment, recent literature seems to have been focused on the positive outcomes of treatment.

Impacts of Stigma

The stigma associated with a mental illness diagnosis leaves many individuals feeling segregated from and rejected by mainstream society at a time when they are facing the greatest challenge of their lives (Marsh, 2000). Stigma is pervasive because it affects every aspect of life for individuals with mental illness (Rubin & Fink, 1992; Satorius, 1998). The impact of stigma ranges from having difficulty in securing housing and employment to accessing appropriate health care. Stigmatization may also affect employment opportunities, because only 10%-30% of individuals with a psychiatric history are employed (Leete, 1992). Additional explanations for the low employment rate may include adjustment to medication, experienced symptoms, and struggles with illness. However, the low employment rate is unfortunate given that employment is one of the most beneficial activities/therapies for individuals affected by mental illness because it allows for participation in life, socialization with others, increased self-confidence, independence, and self-sufficiency. These benefits are reportedly absent when individuals receive government income assistance (Leete, 1992).

Satorius (1998) asserted that stigma also affects financial resources available to assist individuals affected by mental illness and their families. Satorius stated that the attitude of policy makers and the general public limits resources allocated to mental health services which may be a result of pervasive societal stereotypes. He did not discuss other explanations for limited financial resources. However, explanations may include fewer financial resources being allotted to the health care system in general and greater allocation of resources to the areas of health care requiring additional resources.

Social Impact

Societal attitudes attribute the cause of mental illness to personal weakness or actions and popular stereotypes portray mentally ill individuals as dangerous and unstable (Brown & Bradley, 2002; Rubin & Fink, 1992; Hayward & Bright, 1997). However, research in the area of treatment impact is not current and therefore may not be reflective of either societal views of psychiatric treatment or anticipated stigma. Dangerousness is one of the most pervasive myths that exists despite statistics that less than 3% of mentally ill individuals are actually categorized as dangerous (Rubin & Fink, 1992). The root of such beliefs can easily be determined; 77% of television portrayals of the mentally ill include violent or dangerous depictions (Rubin & Fink, 1992). Furthermore, stereotypes are entrenched because the news media sensationalize violent acts committed by mentally ill individuals (Brown & Bradley, 2002; Rubin & Fink, 1992).

Another important result is that diagnosed individuals experience ostracism from society and report living an isolated and lonely life. Mental illness becomes an element of shame and sometimes needs to be kept secret and not disclosed even to friends and family (Leete, 1992). As a result, many individuals experience loss of support, isolation, decreased self-esteem, and feelings of inadequacy (Hatfield & Lefley, 1993).

Addressing Stigma

One of the primary goals according to an American document *In Mental Health: A Report of the Surgeon General* was to address the stigma associated with a mental illness diagnosis (Acuff, 2000; Brown & Bradley, 2002). A suggested strategy included dispelling myths by providing accurate public education to address media portrayals that reinforce stereotypes of mental illness. Attempts at addressing stigma would likely result in increased societal access to mental health services because the general public may gain a more accurate understanding of mental illness and perhaps even recognize signs and symptoms in themselves, acquaintances, or loved ones. Education would address stigma by providing accurate information that could result in addressing and dispelling myths in addition to presenting the face of mental illness as being less dangerous and mysterious than currently portrayed in popular media. Another positive outcome may include affected individuals being more amenable to access mental health services for treatment and possible increased support by family and friends due to less stigma associated with diagnosis.

A second theme that emerged addressed pathology-based models of mental illness as destructive and diagnostic labels as stigmatizing brands. Although it is acknowledged that labels convey much information about an individual's health status, mental health professionals must always remain cognizant that an individual may be affected by a mental illness but that they are never the diagnostic label itself.

Treatment of Mental Illness

Historical Overview

Throughout history the cause of mental illness has been explained in various ways resulting in many forms of treatment. In North America during the 17th century the predominant view was that the insane were incurable and that their condition was a result of personal actions or demonic possession (Allderidge, 1990; Gamwell & Tomes, 1995; Grob, 1994). In the second half of the 18th century explanations of madness based on demonic possession were less pronounced, and naturalistic explanations of mental illness gained popularity. Accordingly the mind-body connection was emphasized, with a balanced lifestyle being viewed as pivotal for both physical and mental health (Grob, 1994).

Unlike in the 17th century when madhouses were commonplace, during the 18th century the mentally ill were largely treated in the community (Shorter, 1997). Social treatments gained popularity and were characterized by love and care by family members. More specifically, families were allocated supplementary finances in order to treat the mentally ill family member at home (Shorter, 1997).

Moral therapy in which the mentally ill were treated with talking therapy and the encouragement of hope instead of harsh treatments such as mechanical restraints was common in the late 18th century (Shorter, 1997). However, during the 19th century the rates of mental illness drastically increased resulting in a shift from treatment in the home to treatment in psychiatric institutions. Psychiatric admissions included individuals expressing extreme behavior such as delusions, hallucinations, and depression. By the end of the 19th century drug administration was extremely popular with hospitals administering drugs up to six times daily to 'restrain' patients in lieu of mechanical or physical restraints (Grob, 1994).

Despite the various treatment of the mentally ill throughout history there seems to be a lack of research into the personal experiences of these individuals. Although documented accounts of the treatment of affected individuals throughout previous centuries provides some insight into their experiences, these accounts fail to provide an understanding of the current experiences of individuals accessing the mental health system.

Satisfaction with Mental Health Treatment

One source of information that provides some insight into the treatment experiences of individuals affected by mental illness can be found in patient satisfaction research. Typically, researchers of consumer satisfaction and experiences of mental health services have focused on interviews or surveys with consumers. Lehman and Zastoway

(1983) conducted a meta-analysis of patient satisfaction with mental health services that suggested that overall patient satisfaction was generally positive. Chronic patients expressed less satisfaction with treatment programs than did non-chronic patients and greater satisfaction was expressed with innovative treatment programs relative to conventional treatment programs. In another patient-satisfaction survey conducted by Pickett, Lyons, Polonus, Seymour, and Miller (1995), outpatients who were satisfied with services reported better psychological functioning, care staff as helpful, therapists as skillful, and treatment facilities as accessible.

In contrast, Coursey et al.(1991) found that outpatients desired additional assistance in dealing with isolation, high levels of unemployment, and low levels of self-confidence. Other findings included a sizable minority of respondents who stated that they were not treated fairly while hospitalized and under half felt that mental health providers had too much power over their lives. Although other statistics regarding satisfaction with treatment and hospitalization were reported, Coursey et al. did not report specific response rates for the findings.

The perception of health care providers is also important when assessing services. The California Well-Being Project (Hatfield & Lefley, 1993) highlighted the discrepancies between clients' and mental health professionals' perceptions of issues relating to respect for clients, confidentiality, and trust. Professionals interviewed in this study generally described their perceptions in a positive manner. More specifically, 66% of the professionals reported that their clients felt safe talking to them about personal issues and feelings, 62% reported that they informed their clients about the potential risks of treatment, and 100% reported that they treated their clients with both courtesy and respect. Interestingly, client perceptions differed because many did not feel that they were adequately informed of the risks and benefits of their treatment plan, were considered to have something valid or important to say, or were listened to. Unfortunately, statistics were not provided in regards to specific client responses.

Treatment Experiences

In addition to satisfaction studies, personal narratives provide insight into treatment experiences. Glass and Arnkoff (2000) reviewed four articles written by individuals who had been affected by and recovered from mental illness. Three themes were evident. The first involved the nature of the therapeutic relationship with mental health professionals. Specifically, what was reported as helpful included practitioners listening and attempting to understand the client's process and experience, client decision making in treatment selection, and facilitation of a recovery expectation. Second, forced commitment to a psychiatric institution and being locked in seclusion were viewed as extremely negative treatment experiences because these types of hospital experiences left patients feeling powerless and degraded (see Bassman 2000; Everett, 2000; Lovejoy, 1982; Lynch, 2000). Concerns were also expressed about the psychiatric professionals' weak emphasis of recovery and insistence on lifelong medication compliance in the treatment of mental illness. Lastly, concerns regarding the myth of the permanent nature of mental illness and the ineffectiveness of psychotherapy with psychiatric clients were identified.

Recovery

The Recovery Vision

Important in the treatment of mental illness has been the concept of the possibility of recovery in the prognosis of mental illness. There has been a gap in the research literature regarding the recovery process of individuals affected by mental illness. The focus of research has largely concentrated on the efficacy of traditional treatment approaches which are generally categorized under the biological model (Anthony, 1993; Pettie & Triolo, 1999).

More recently, experiential accounts by affected individuals and long-term research studies have been impacting the research agenda in the mental health field. In addition to great advances in treatment and understanding the causes of mental illness, researchers must move beyond the scope of pathology and physiology to examine more thoroughly the realm of healing in order to better facilitate recovery (Anthony, 1993).

The recovery vision is founded on the belief that affected individuals can grow beyond the limitations of their illness (Anthony, 1993). This ideology may greatly facilitate hope and motivation instead of fostering passive submission to a diagnosis and medical prognosis. The definition of recovery appears vague because little is known about the process (Frese & Davis, 1997); however, the concept is visionary and the potential impact profound on the treatment focus and prognosis of a mental illness (Anthony, 1993).

Traditional medically orientated models have defined recovery by individuals as their being less impaired, disabled, and disadvantaged than prior to medical treatment. In contrast, the recovery vision focuses less on symptomology and impairment and more on meaning in life and success in daily functioning (Anthony, 1993). Most treatment programs have focused on short-term treatment options or lifelong maintenance instead of recovery despite the fact that researchers have indicated that many individuals either substantially improve or recover from their condition (Leete, 1989; Ridgway, 2001).

Recovery Defined

Recovery is described as a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and roles. It is a way of living a satisfying, hopeful, and contributing life even with one's limitations. Recovery involves the development of new meaning and purpose in life as one grows beyond the catastrophic effects of mental illness (Anthony, 1993). It is possible without complete symptom management; a recovered individual may still experience powerful symptomology and some degree of difficulty in daily functioning. However, individuals may experience restored task/role performance and effectively remove opportunity barriers that may have been hindering functioning as a result of stigma (Anthony, 1993).

Recovery is not a linear process because it includes setbacks and periods of great and little change (Anthony, 1993). It is not characteristic of sudden or drastic transformation (Ridgway, 2001). The process of recovery is often long and complex, frequently extending beyond the effects of the illness itself. Anthony indicated that individuals may also need to address the effects of stigma, hospitalization, unemployment, and the realization that one's dreams and goals may have to be modified or reexamined. Hopes for recovery may be easily dashed as a result of pervasive messages from medical professionals that mental illness results in lifelong disability (Frese & Davis, 1997).

Recovery and the Personal View of Self

During the recovery process an individual's understanding of him/herself may change. Following the onset of a mental illness, an individual may begin to perceive two versions of him/herself. One is the person he/she used to be and the other, the person he/she has recently become (Pettie & Triolo, 1999). Generally, the former self is perceived as more successful and healthier and therefore efforts to return to the previous self are made. Part of the process includes beginning to reconstruct one's identity to become respectful and comfortable with the new self (Davidson & Strauss, 1992; Pettie & Triolo, 1999). A crisis may emerge as one begins to reconcile the present self with the desired self (Pettie & Triolo, 1999). Stigma may greatly undermine a person's efforts at improving him/herself as the individual may be vulnerable to negative input from others while in the process of reevaluating or reconstructing his/her identity (Davidson & Strauss, 1992). Also a diagnosed individual may internally stigmatize him/herself due to personally held misperceptions of mental illness and its limitations.

Common Themes in Recovery Narratives

First-person narrative accounts indicate that recovery may occur without professional intervention because individuals affected by mental illness hold the key to recovery. Therefore the role of mental health professionals in the recovery process is largely a supportive one. Recovery seems to be enhanced by professionals, specifically psychiatrists, who work with individuals to find effective medication control for symptoms (Jacobson, 2001). Whether or not to take medication seems to pose a dilemma for many individuals. Medication compliance is viewed by many as necessary to address the biological nature of mental illness. However, a recent emphasis on self-management suggests that individuals should be able to reduce their dosage of medication and effectively manage their illness. Consequently, individuals who unsuccessfully wean off medication may view themselves as failures (Jacobson, 2001).

Recovery can occur despite the continuation of symptomology. A sign of recovery may include symptom reoccurrence being perceived as less threatening to one's recovery and decreased intensity, frequency, and duration of symptoms resulting in less interference with overall functioning in daily life (Anthony, 1993). Once symptoms are addressed through medication, individuals are better able to deal with the social ramifications of being mentally ill (Jacobson, 2001).

Recovery from the consequences of being mentally ill may be more challenging than recovering from the mental illness itself. Factors that inhibit the recovery process include inability to perform valued tasks and roles, loss of self-esteem, and dealing with issues of disability, dysfunction, and disadvantage. Barriers resulting from a mental illness diagnosis may include loss of rights, barriers to equal opportunities, and discrimination. An example of possible barriers includes the difficulty experienced by many individuals in finding adequate housing and employment (Anthony, 1993).

A common denominator in the recovery journey is support of the person affected by mental illness in his/her time of crisis (Acuff, 2000; Anthony, 1993; Ridgway, 2001). More specifically, individuals in recovery talk about "people who believed in them when they did not even believe in themselves, encouraged their recovery but did not force it, who tried to listen and understand when nothing made sense" (Anthony, 1993, p. 18). The recovery process may be encouraged by support systems such as families, friends, and support groups (Acuff, 2000; Anthony, 1993; Chadwick, 1997; Leete, 1988). Peer support involvement or self-help groups seem to facilitate a sense that individuals are experts in their own lives and that they have the ability to solve their own problems (Jacobson, 2001; Leete, 1988; Ridgway, 2001). Leete suggested that support groups are helpful by providing a place to belong as a result of being rejected by society. "Support groups can give us the personal strength and commitment to overcome the stigma, prejudice, discrimination and rejection we have experienced to reclaim our personal validity, our dignity as individuals, and our autonomy" (p. 48).

However, Chadwick (1997) warned that constantly being around others in the subculture of mental illness may lead to individuals taking on a 'mental patient' identity. Even though one may no longer be hospitalized there is a tendency to create invisible walls around oneself by not experiencing anything outside the subculture. Chadwick suggested that going to movies, libraries, and parks may help remove the invisible walls and aid the transition to community living, which may facilitate and enhance the recovery process.

Part of the recovery process is moving from extreme social withdrawal and isolation to engagement and active participation in life (Davidson & Strauss, 1992; Ridgway, 2001). Individuals begin to actively participate in life by socializing, volunteering, working, and pursuing hobbies and interests (Ridgway, 2001). Therefore, recovery is characterized by active coping rather than passive adjustment. Active coping is a relatively new concept; traditionally passive adjustment has been encouraged by mental health and medical professionals resulting in adaptation to permanent disability. In active coping individuals become aware of their personal triggers, effective coping strategies, and resources and begin to self-monitor in order to manage symptoms of illness (Jacobson, 2001; Ridgway, 2001). Individuals may reevaluate what they are realistically capable of doing. For example, they may ask themselves the question, "Am I really ready to go from part-time to full-time employment?" (Davidson & Strauss, 1992).

Recovery entails reclaiming a positive sense of self and no longer viewing oneself primarily as a person with a psychiatric disorder. Prior to recovery, individuals may feel defined by their mental illness, coming to view themselves exclusively in terms of their diagnosis. However, during recovery a new sense of self distinct from the diagnosis emerges (Davidson & Strauss, 1992; Jacobson, 2001). As a result, the mental illness becomes a fact of one's life but not the defining factor of one's life. Before engaging in the process of recovery, individuals may deny their difficulties; however, in recovery they may accept and learn to understand the challenges posed by their illness

(Ridgway, 2001). As such, recovery involves breaking through denial and achieving self-understanding and acceptance.

Recovery involves moving from alienation to a sense of meaning and purpose. In recovery, individuals reacquaint themselves with their strengths and talents which aids in enhancing personal dignity and self-esteem. Recovery narratives generally describe moving beyond personal goals and becoming actively involved in helping other individuals affected by mental illness begin their own journey of recovery (Ridgway, 2001). Accordingly, a common theme found throughout recovery narratives includes educating oneself about a mental illness diagnosis and then educating others to increase awareness and understanding of the condition (Jacobson, 2001; Ridgway, 2001).

Recovery from a mental illness is not indicative that one was 'not really mentally ill.' At times, individuals who recover from mental illness are discounted as not having been affected by a mental illness in the first place. As a result, their recovery process is not viewed as an exemplar that could provide hope and encouragement for others (Anthony, 1993).

Although first-person narratives provide tremendous insight and information about the experiences of individuals affected by mental illness there are limitations when relying on published narratives. These may include the selection of narratives from a small number of published journals that therefore represent an atypical recovery process by extraordinary individuals. Additionally, the findings may not be characteristic of all individuals affected by a mental illness (Ridgway, 2001). Despite these limitations, personal narratives provide rich information regarding the process of recovery, treatment experiences, and the strengths and weaknesses of the mental health system.

Summary

Despite the fact that mental disorders comprise the greatest proportion of disability in the world, little is known about the treatment experiences of individuals affected by mental illness (Satorius, 1998). Until recently, research has generally ignored the experiences of these individuals. However, during the past decade personal narrative accounts have become more common in the area of rehabilitation and recovery. This research has facilitated greater understanding of the experiences of individuals affected by mental illness. Qualitative research exploring a more holistic understanding of the experiences of individuals affected by a mental illness has been generally overlooked in the labeling, stigma, and hospitalization literature. Therefore, the purpose of this research was to explore the question, "What are the experiences of individuals affected by mental illness?” The following chapter includes a description of methodology and procedure incorporated into this research. Specifically, a general discussion of phenomenological research, participant selection, data collection, bracketing, and data analysis is addressed.

CHAPTER THREE

METHOD

Qualitative inquiry is used to investigate the quality of a particular activity rather than how often it occurs or how it would otherwise be evaluated. The emphasis is on holistic description; that is, describing in detail all of what goes on in a particular activity or situation (Fraenkel & Wallen, 2000). This exploration and description of human experience enhances understanding of personal perspectives and experiences (Patton, 1990).

The Phenomenological Method

Within the qualitative paradigm, phenomenological inquiry is aimed at gaining a deeper understanding of the nature or meaning of everyday experiences through descriptions of experience (Van Manen, 1990). The phenomenological method "remains with human experience as it is experienced" (p. 53) and involves contacting the phenomenon as individuals experience it (Colaizzi, 1978). The method of description allows for the relaying of experience without denying or denigrating it (Colaizzi, 1978). Phenomenology does not attempt to explain or control the world; instead, it "offers the possibility of plausible insights that bring us in more direct contact with the world" (Van Manen, 1990, p. 9). From this viewpoint, minimal interest is expressed in the factual matter of experiences; for example, in the determination of authenticity or frequency of experiences. The nature of experience reveals "the lived quality and significance of the experience in a deeper manner" (Van Manen, 1990, p. 10).

Rationale for Qualitative Research

Qualitative methods allow for participants to relay their experiences, feelings, and opinions in a personally meaningful way. This process facilitates gaining a better understanding of the processes that impact an individual's life. Therefore, the utilization of this approach was deemed to be appropriate in gaining an understanding of the experiences of individuals affected by mental illness.

Rationale for Interview Method

Data were obtained through interviewing participants who had been previously hospitalized and diagnosed with a mental illness.

> The fact of the matter is that we cannot observe feelings, thoughts, and intentions; . . . we cannot observe how people have organized the world and the meaning they attach to what goes on in the world. We have to ask people questions about those things" (Fraenkl & Wallen, 2000, p. 509).

A semi-structured, open-ended interview was utilized, which provided some inquiry into specific experiences of the participants while allowing flexibility for participants to relay their experiences in their own meaningful way.

Bracketing

Epoche is the first step in phenomenological analysis. During this stage "it is essential that the researcher eliminate, or at least gain clarity about, preconceptions" (Patton, 1990, p. 407). Rigorous self-reflection and identification of personal biases are essential, and therefore awareness of preexisting prejudices and assumptions regarding the experiences of individuals were thoughtfully considered. This was an important aspect of the research process, because I have had considerable experience in interacting and engaging in discussion with individuals affected by mental illness as a result of a previous research study. Bracketing allowed me to be thoughtful of personal biases and assumptions throughout the process of data collection and analysis. This process facilitated the presentation of data in a manner that was reflective of the participants' experiences. A personal journal was kept throughout the research process to record and reflect on thoughts, feelings, and personal biases.

Participants

The participants were five individuals with a mental illness diagnosis from a drop-in center located in a small city in central Alberta. The sampling for the study was purposive: The participants met selection criterion in order to participate. The criteria for participation were as follows: (a) were between 18 and 50 years of age, (b) had received a psychiatric diagnosis by either a medical doctor or a psychiatrist, (c) were currently taking medication for the treatment of mental illness and currently under the care of either a medical doctor or a psychiatrist, (d) had been hospitalized for mental illness, and (e) had been out of the hospital for at least six months.

The participants consisted of three females and two males (two Caucasian males, two Caucasian females, and one Aboriginal male), ranging from 36 to 44 years (M = 40 years). Diagnoses included schizophrenia, manic depression, and bi-polar disorder. Two participants reported a dual diagnosis, and one reported having three simultaneous mental illness diagnoses. Hospitalizations for treatment in either psychiatric facilities or general hospitals ranged from four days to two-and-a-half months (M = 27.4 days), and the total number of hospitalizations ranged from two to eight (M = 4.4 hospitalizations).

Procedure

Once ethics approval was granted by the University of Alberta, permission was obtained by the manager to place a poster in the drop-in center advertising the nature of the study and specifying participant criterion (see Appendix A). The drop-in center is a community mental health facility where individuals may socialize, engage in activities, and access support. Ten potential participants contacted the researcher, and five met the outlined selection criterion.

A verbal research summary was provided to all potential participants before the researcher verified selection criteria with all participants. A research overview that provided a detailed description of the study and participation expectations was provided to screened participants (see Appendix B).

The information contained in the overview was explained to the participants in general terms to ensure understanding. A consent form was then provided and verbally summarized by the researcher in order to facilitate informed consent. The right to withdraw from the study without prejudice was also verbally reiterated and the participants were asked if they had any questions or concerns. All participants signed the consent form indicating that they understood the nature and purpose of the research and were willing to participate. Signed consent forms (see

Appendix C) were filed separately from the data in order to ensure confidentiality and anonymity.

Following general demographic questions regarding age, diagnosis, and number and length of hospitalizations, a semi-structured interview was conducted. The researcher addressed seven pre-identified questions targeting hospitalization, diagnosis education, connection to community agencies, and personal impact of the diagnosis and illness (see Appendix D). All seven questions were asked of all participants. Questions were asked in a predetermined order; however, if the participants initiated discussion regarding related topic areas, they were not hindered from sharing their experiences in their own meaningful way. Other questions relevant to the purposes of this research were included in the semi-structured interviews as appropriate. These additional questions varied between interviews, were dependent on the participant's ability to recall and describe experiences, and therefore were not asked of all participants. All interviews were audiotaped and then transcribed verbatim by a professional transcriber, checked for accuracy by the researcher, and coded by the researcher for common themes.

Data Analysis

Data analysis was based upon the work of Colaizzi (1978) and Osborne (1990); the following description outlines the analysis utilized in this study. First, completed interviews were transcribed into text, resulting in the formation of a protocol; that was then read several times in order "to acquire a feeling for them" (Colaizzi, 1978, p. 59). Then significant statements or themes were extracted from the protocols with repetitions and irrelevant descriptions eliminated. The next step was formulating meanings which is what Colaizzi characterized as interpreting the meaning of each significant statement. In this step the researcher "leaps from what subjects says to what they mean" (p. 59) while still reflecting the context of the original protocol. Common themes were then clustered (Osborne, 1990) to produce a higher order cluster of themes. Performing these steps for each interview constituted a within-person analysis.

Afterwards, a between-person analysis was conducted in order to compare and contrast themes between protocols. The majority of themes were consistent between protocols, and unique themes were also included. Next, cross referencing of the higher order clusters with original protocols was then completed. This procedure validated higher order clusters by determining whether information in the original protocols was accounted for in the higher order clusters. Verification ensured that themes not evident in the original protocols were not implied in the clusters of themes (Osborne, 1990). Finally, narratives were written for each participant.

The following chapter is an introduction to the five participants of this study. Information presented differs among various participants as a result of their unique life experiences. The background information provided is intended to provide a context in which to interpret the results.

CHAPTER FOUR

INTRODUCTION TO THE PARTICIPANTS

Five participants who were willing to share their treatment experiences as well as related topics were interviewed. The beginning portion of the interview involved the participants recalling factual events related to their diagnosis and treatment experiences. The time was also used to establish rapport before more personal questions were asked. Predetermined questions were asked of all participants; however, because the interviews were semi-structured, they varied in content. The following are brief biographies of the five participants, which provide some background to interpret the results of this study. Personal details have been altered to protect the anonymity of the participants.

Jim

Jim was a 36-year-old male who was diagnosed with bipolar disorder and schizophrenia by a psychiatrist in 1987. Hospitalized six times between 1987 and 1995, Jim was forced into being admitted to a psychiatric hospital for treatment in 1987 by his family. Forced hospitalization added to his existing fears of psychiatric hospitals from television and movies. Jim described the overall experience of being treated for his condition as extremely difficult. Specifically, he stated that he lost his wife, children, and many of his friends as a result of his struggle with his condition. This added to the stress of coping with his illness as he found himself with fewer individuals to whom to turn for encouragement and support. No indication was given as to when his relationships were negatively impacted.

Jim recalled that his worst experience of hospitalization was being surrounded by individuals who had more severe conditions than his. His sense of uneasiness resulted in his being very aware of his safety in the presence of other patients. Jim was greatly affected by a man who, isolated from other patients, screamed throughout the night and in the morning was carried out of his room on a stretcher because he was dead. For many years after his discharge Jim had terrible memories of this incident and stated that patients with severe conditions should be treated separately from patients with mild and moderate conditions.

During one hospitalization Jim turned to the Mission Foundation at the hospital for support. He remembered the songs that fostered his sense of hope. The support facilitated by the chapel enhanced and strengthened his belief that he would get better. The caring, friendly, and encouraging staff also aided his adjustment to hospitalization and improvement in his condition.

Jim indicated that the misconceptions that he had about mental illness from television resulted in many years of denial of his condition after diagnosis. Furthermore, he was not compliant with medication because compliance would have been an admission that he was not well. Once Jim accepted his diagnosis, he complied with medication and consequently realized that he felt better as a result of it. When feeling better, Jim educated himself about mental illness in order to gain a personal understanding of his condition and to help other individuals who had been diagnosed.

Jim became more compassionate as a result of acceptance of his condition. Specifically, he described himself as self-centered prior to becoming ill and more empathetic and understanding of others since acceptance of his illness. Despite this positive change, Jim wished that he did not have a mental illness because of his daily struggle with staying well.

Jim maintained a belief in the possibility of recovery despite his struggle with his illness. He was reminded that his mental health remained fragile because he had experienced difficulty with medications and side effects. Jim now dealt with this struggle by accepting his condition and reminding himself that the Lord was always with him. He attributed his daily connection with his second wife and garden as being pivotal to staying well.

Fred

Fred was a 43-year-old man who was diagnosed with schizophrenia by a psychiatrist approximately 20 years ago and has been hospitalized twice. When Fred initially experienced symptoms, he shared his concerns with his parents who assured him that there was nothing wrong with him. This concerned Fred because he knew that his experiences were not normal and he did not know where to turn for help. He felt that because he was seeing things and hearing voices, the illness had taken over his whole body. As Fred's illness worsened, he sought help at a general hospital and agreed to psychiatric hospitalization for treatment.

Fred described hospitalization as a negative experience because of poor staff treatment. Fred recalled that the psychiatric nurses would call him derogatory names to antagonize him in an attempt to isolate him. Fred saw this occurring with other patients and therefore ensured that he did not get angry at the comments the nurses made. Despite this, Fred indicated that his experiences with the doctors were positive because they were kind and engaged in conversations with him.

After Fred was discharged from the hospital, his understanding of his diagnosis consisted solely of the symptoms he experienced because he had not received diagnosis education. He asked his sister to assist him in accessing information and stated that he was confused to find out that schizophrenia is hereditary because no other family members had been diagnosed.

Fred struggled to find a medication and tried several before finding an effective one. Once a medication was found, his life improved, and he no longer experienced symptoms. Currently, he was compliant with medication but often wonders what would happen if he stopped taking it. Fred's fear of relapse hinders him because of his awareness that there was no known cure for schizophrenia. Fred did not discuss how his diagnosis had impacted his life.

Joy

Joy was a 38-year-old female who was diagnosed with paranoid schizophrenia and bipolar disorder by a psychiatrist and was hospitalized eight times in the last six years. Joy indicated that it was difficult to be around patients during her hospitalizations because of her general fear of being around people. Once while hospitalized she was forced to be near some patients who were violent. In order to cope with her fear of others, Joy stayed in her room while her five roommates were out of the room and stayed awake while they were in the room to ensure her personal safety.

Joy found the hospital staff to be very caring and helpful. In addition, her psychiatrist listened to her which was very important to her. Currently, her family doctor also listens to her which was an improvement over previous doctors that she had had. She explained that once she had had a doctor who had dismissed her mental health concerns which lead her to question her experiences and believe that she was a hypochondriac. Joy did not specify how long she believed this, however in the meantime she abstained from accessing medical treatment and consequently her condition worsened. When Joy was finally diagnosed with paranoid schizophrenia and bipolar disorder, she felt relieved because her diagnoses provided an explanation for what she had experienced.

When Joy was discharged from the psychiatric hospital, she was not educated about her diagnoses. After a period of time following diagnosis, she asked questions about her diagnoses and treatment options. Currently, Joy had a mental health therapist, mental health worker, physician, and drop-in center staff from whom she was able to obtain information when she had questions regarding her condition.

Joy's diagnosis impacted her life in a positive manner as she now better understood her experiences as well as what she required to cope with her condition. Joy realized that she needed to push herself to go outside, engage in activities, and socialize more. Her success in engaging in these activities increased her quality of life. In addition, Joy stopped self-medicating with alcohol and drugs to alleviate her symptoms when she received effective medical treatment.

Joy believed that individuals with a mental illness can have a good life by engaging in beneficial activities but she questioned her belief in recovery because she defined recovery as no longer having a mental illness. Despite her doubts, both her physician and her mental health worker indicated an improvement in her condition. Her acceptance of recovery varied daily. When Joy felt well, she believed in the possibility of recovery; however, on the days when she struggled with her condition, Joy believed that she would never recover.

Joy indicated that the mental health services, the psychiatric hospital, her physician, and the drop-in center staff helped in her struggle with her condition. The drop-in center was especially helpful because she could access support and acceptance from both staff and members. Her mental health worker was also useful because she listened, encouraged, and provided support. Joy suggested increasing staff at both mental health services and psychiatric hospitals and adding more beds to psychiatric hospitals to improve services for consumers. She recalled that once when she was hospitalized, the staff were extremely busy and were unable to attend to her personal needs. Being overlooked left Joy feeling hurt and questioning the value of hospitalization.

Joy has experienced stigma from a woman who lived near her who stated that she did not want her child around Joy. She related feeling confused and hurt by this woman's statement, because Joy would never hurt a child and the woman probably believed that she was crazy. She attempted to deal with being rejected by reminding herself that she was a good person. Joy stated that stigma still hurts her although she attempted to cope with it one day at a time. In addition, Joy's brother had told her that she was crazy. As a result of his rejection, their relationship has suffered and they did not communicate with one another. Consequently, Joy did not share her diagnosis with others because she was afraid of further stigma and rejection.

Nina

Nina is a 39-year-old woman who was hospitalized three times and diagnosed with clinical depression in 1998 by a psychiatrist. During her first hospitalization for a suicide attempt, she felt that the staff did not believe that her condition warranted hospitalization. Nina felt that her difficulties were dismissed because of the fact that she was verbal and presented as intelligent. Nina sensed the staff's lack of concern towards her condition and requested a discharge.

Nina continued to feel suicidal, which left her feeling panicked because she knew that she required treatment. Nina decided not to share her mental health concerns with her family; she feared that they would make inaccurate judgments about her ability to make decisions for herself. It was extremely difficult for Nina to get through each day. Finally, Nina shared her experience with her boyfriend at the time; however, he failed to understand why Nina was suicidal and was not supportive of her. His lack of understanding and support left Nina feeling confused about what course of action she should take.

Nina's condition worsened and she began slashing her arms. Her aunt found out and informed the family. Then she encouraged Nina to visit a doctor. The three of them decided that re-hospitalization would be beneficial. However, Nina felt that she had to agree to re-hospitalization only because her family was convinced that they knew what was best for her.

Upon re-hospitalization, Nina felt that the staff minimized her experiences and mental health concerns. This time her perception was based on staff's comments that suggested no reason to continue hospitalization. Nina decided that if the staff felt that her condition did not warrant hospitalization, then she no longer wanted to remain at the hospital. Consequently, Nina requested a discharge.

Within a year Nina was suicidal again, but this time she accessed mental health services and was hospitalized immediately. During her third hospitalization, she shared what she was feeling with the staff and she felt that this time they expressed an interest in her condition. Their genuineness made it easier to share her personal feelings and concerns. She found hospitalization to be helpful and indicated an improvement in her condition.

Once diagnosed with clinical depression, Nina educated herself about her condition. The hospital staff had not provided diagnosis education but she accessed information through pamphlets available at mental health services. The information provided a sense of relief because it addressed many questions that she had about her condition.

Nina described experiences with the mental health services and the drop-in center as positive. The staff at these agencies provided her with support and understanding which have aided her in addressing and dealing with her difficulties. Although Nina believed that it would entail a miracle for her to recover, she attempted to stay well by socializing at the drop-in center, maintaining contact at mental health services, and spending time with her family.

Nina stated that she did not want to have a mental illness and that upon being diagnosed, she made negative judgments about herself based upon her beliefs about mental illness. Although, Nina accepted her condition she felt that her illness did not allow her freedom in life because she always had to be aware of personal triggers such as stress, that exacerbated her condition. She added that she would like to experience life without depression.

Donna

Donna is a 44-year-old woman who was hospitalized three times and diagnosed with bipolar disorder by a psychiatrist. Donna described psychiatric hospitalization as excellent because of the quality of care she received. Despite this evaluation, her primary goal while hospitalized was to escape but she was prevented from doing so because of being treated on a locked ward. Donna revealed that her fear of being hospitalized came from watching television and movie portrayals of mentally ill individuals and psychiatric hospitals. Consequently, upon admission to a psychiatric hospital, she anticipated experiences such as being restrained in a straitjacket which resulted in an attempt to escape by ringing the fire alarm.

During her first hospitalization, Donna was involved in a treatment process that excluded her husband. She felt that this approach was unfair because her husband would be her primary caregiver once she was discharged. However, her husband was much more involved during her second hospitalization. Specifically, he was able to decide independently whether she was ready to go home on weekend passes and whether she was well enough to be discharged. Although his involvement was generally positive, Donna recalled a negative meeting with her psychiatrist and husband in regards to her discharge. She initially met with the psychiatrist to discuss her mental health status and then her husband joined the meeting. Donna was expected to listen without interrupting while the psychiatrist and her husband discussed her condition and decisions regarding her discharge. It was very difficult for Donna to be excluded from decisions that were going to impact her and she cried throughout the meeting.

The last time that Donna was discharged from the hospital, she left while taking an ineffective medication that did not completely address her symptoms. She felt that this was a result of a lack of available beds and staff. Consequently, Donna relied on her community psychiatrist to help her find an effective medication. This psychiatrist also involved Donna's husband in treatment decisions and planning by reporting whether she was experiencing difficulties in daily life. Donna was thankful for a supportive husband throughout her hospitalizations and relapses.

In order to stay well, Donna needed to have a reason to get out of bed in the morning. Having a part-time job provided Donna with meaning and purpose in life and without employment she believed that she would have had to be re-hospitalized. Donna believed that staying well also entails a focus on daily goals and not on past failures or setbacks. Lastly, Donna added that the drop-in center is important because it provides a medium to access support, acceptance, and socialization.

The following chapter is a presentation of both common and divergent themes identified in the interviews with the five participants of this study. Personal experiences that are exemplars are presented in excerpts from the transcripts.

CHAPTER FIVE

RESULTS

This chapter is a presentation of information gathered through the interviews conducted with the participants of this study. Presentation of interview content includes both unique and common themes. Experiences of the participants are presented through excerpts from interview transcripts in order to provide insight into treatment experiences, the impact of diagnosis, stigma, recovery, and suggestions to improve the mental health care system.

Hospitalization and Treatment Experiences

Fears of Hospitalization

Donna, Jim, Fred, and Nina described the period of time prior to hospitalization as stressful because they did not know what to anticipate once hospitalized. Fears were based on limited knowledge of mental illness and stereotypes of mental illness and psychiatric hospitals from popular media, such as television and movies. Donna stated

> Well, you see, *The One That Flew Over the Cuckoo's Nest*, you know, movies like that, and that is all you know about mental institutions. They do not advertise what they do, so you got nothing to gauge on but fear.

In addition, Jim and Donna both described their families as feeling fearful of hospitalization because of a lack of accurate knowledge of mental illness. Jim indicated that his mother refused to visit him while he was hospitalized and discouraged many family and friends from visiting. He stated that this was because of her own fears of mental illness based on misinformation and stereotypes.

Limited knowledge of mental illness contributed to fears of accessing treatment, which resulted in misperceptions of what hospitalization entailed. Fears were compounded in individuals who are unwillingly hospitalized and committed. Jim relayed that arriving at the hospital "was the worst because I had no idea of what it was like in a mental hospital. I knew once I passed those doors that I was locked inside."

Jim, Donna and Nina recalled knowing very little about mental illness, and the information that they possessed was based on negative stereotypes. Furthermore, Jim stated being informed that he had a mental illness was frightening because of his belief that individuals with a mental illness were crazy. Once he started to learn about mental illness, he was more accepting of his diagnosis. However, he did not educate himself until a few years after diagnosis.

In contrast, Joy did not indicate being fearful or apprehensive about hospitalization. Rather, she described feeling relieved that she would be receiving treatment that would address her bothersome symptoms which were negatively impacting her daily functioning.

The participants provided some insight into the feelings and beliefs that they had held prior to hospitalization. Their experiences identified misconceptions and stereotypes that contributed to apprehension of hospitalization prior to admission. In contrast, one participant recalled positive anticipation of treatment. Information from these interviews generally suggests that prior knowledge based on stereotypes seemed to increase levels of stress and fear.

Hospitalization

Both positive and negative hospital treatment experiences were shared by the participants. Nina, Joy, Donna, and Jim stated that once they were admitted to a psychiatric hospital, they were unable to identify with other patients as a result of perceiving their own difficulties as less severe. Nina stated, "I just didn't feel like I was one of the patients because I saw patients in there that were probably delusional. Some had really bad behaviors, and I just did not feel like I was one of them."

Similarly, Joy recalled feeling a sense of separateness from other patients and stated that her experiences were frightening. She indicated that during her last hospitalization she had shared a room with five female roommates whom she avoided because of her fear. Joy's fear of other patients was echoed by Jim. He felt that he needed to be on guard from the other patients in order to remain safe. Feeling unsafe was also experienced by Donna, who indicated that her primary objective while hospitalized was to escape. She revealed that if she had not been treated on a locked ward, she would have escaped without being treated for her condition.

In regards to treatment by staff members, the participants relayed some negative interactions with the psychiatric nurses. Fred was insistent that the nurses were not friendly to him. In fact, he stated, "Some of the nurses are mean. Like, they would try and say something to make you mad, and then they would throw you into that little room. That is what they would try and do with me."

In addition, Nina recalled during two separate hospitalizations that she had the distinct impression that the nurses did not believe that her condition warranted hospitalization. This left her feeling angry and her experiences minimized. Consequently, she requested a discharge. She described that, while hospitalized, "I felt like I was taking up space. I thought, Well, okay, you work here, so if you think so, I'll go. So I talked to the psychiatrist and I had him check me out."

Joy also felt that she was occupying needed space in the hospital. She recalled that the nurses were very busy and therefore she was unable to talk to them or receive support from them. This lack of personal attention left her questioning why she was at the hospital.

The participants also expressed concerns regarding the placement of patients with more severe conditions with those with less severe conditions in hospitals. They expressed fear of individuals who were aggressive and violent and who screamed or yelled. Joy described her experience of being around these patients as "scary. I did not know what to do or how to handle that kind of thing. So it would be nice if they could hook up people that have similar types of problems."

Despite reported negative experiences while hospitalized, the participants also recalled positive experiences. Joy stated that her psychiatrist scheduled time to talk to and listen to her which she found very helpful. Fred also stated that having his psychiatrist invite him into his office to talk about his experiences and feelings was meaningful because he felt heard and important. He relayed that despite his negative interactions with the nurses, the hospital doctors and psychiatrists were kind and caring.

During Nina's third hospitalization she found the nurses acknowledging the severity of her condition, helpful, and kind. More specifically, she stated that the nurses were

> talking with me and being available and approaching me if I needed to talk, and they sensed that maybe something was going on. Or if I was isolating myself away from the other patients, they would approach me and ask me what was going on, and we would sit down and talk.

Donna described her overall experiences of hospitalization as excellent. Specifically, she identified the quality of care that she received from staff and the extensive testing to evaluate her health status as impressive. Her positive evaluations of the hospital staff indicated that the nurses were "very empathetic, very accepting. They listen. You know, if you were a babbling idiot that day it did not matter; they would sit and listen."

Similarly, Jim considered the staff attentive as he recalled a male nurse who invited him to go for coffee and an afternoon airplane ride. Jim also remembered his experiences with the Mission Foundation as aiding him in coping with hospitalization. Specifically, he identified the chaplain, the hymns, and the connection that he experienced with God as greatly contributing to his hope of getting better. Furthermore, they aided in overcoming his thoughts of committing suicide during times that he believed that he would never feel better while hospitalized.

Overall similar negative aspects of hospitalization were experienced by the participants, such as non-identification with other patients and feeling a lack of validation by the psychiatric staff. Despite the reported negative experiences, positive experiences were also identified that included feeling listened to by staff, feeling important and accepted, and having someone to whom the participants could talk.

Community Treatment Experiences

Following discharge from the hospital, the participants accessed community treatment such as mental health services, physicians, community psychiatrists, and support at the local drop-in center. Both negative and positive experiences were reported.

The physician Joy had prior to hospitalization left her questioning herself and feeling as though she was a burden on the medical system. When Joy voiced her mental health concerns to her doctor, she stated

> I would go home thinking I was crazy. Like, I had nothing wrong with me, yet I was feeling all these feelings, and I could not deal with them, all the noise in my head and stuff, and they were saying that it was nothing. It just really bothered me. And then I was feeling like I was a hypochondriac, and I quit going, and it just got worse and worse.

Joy stated that these interactions resulted in her no longer accessing medical treatment. Jim recalled a similar experience because he felt that his physician did not address his expressed health concerns. This resulted in ineffective medical treatment that left his symptoms un-addressed. He felt that his symptoms were

> terrible, . . . and I would tell the doctor and he would just want to leave well enough alone. When I told my new doctor what happened, just bang, . . . he adjusted the medications. I didn't have that trouble any more; I was a whole lot better.

Donna and Fred also had doctors who were inattentive to personal concerns and hesitant to change medications. These participants also stated that they were treated by physicians who left them feeling unheard which resulted in their symptoms being un-addressed.

Nina was also dissatisfied with that quality of care that she received from her physician. Specifically, she recalled that he was disinterested in her condition because he failed to address some of her expressed health concerns. In addition, Nina stated that her physician

> just talked down to me, and that pisses me off, people who treat me less than my intellectual level. So I switched doctors, and I found a doctor that I am comfortable with and that takes an interest in my diagnosis and what is going on with me.

In contrast, a physician who was attentive to Donna's needs and who listened to her concerns and experiences was helpful. Fortunately, her community psychiatrist worked closely with her to find an effective medication with few side effects. Donna reported that this process spanned five years and that her psychiatrist was attentive to both the effectiveness of the medication and her personal evaluation of both the side effects and the way that the medication made her feel. Donna was pleased with the care that she received and described her psychiatrist as caring and attentive.

Similarly, Fred reported that his current physician was attentive to his concerns and listened to him. In addition, Jim indicated that his mental health therapist, psychiatrist, and drop-in center staff have been very helpful. He stated

> I feel that [the mental health professionals] are trying to work with you and not just on their own terms. They are working with you to do whatever they can to make your life the best that they can, as fast as they can.

In addition to formal treatments, all participants unanimously indicated that they found that their local drop-in center was a source of acceptance, understanding, and support. Nina described the drop-in center as "pretty much a lifesaver. I had some place to go, people who understand, people to talk to, people who accept me without making judgments of me or stigmatizing me."

Joy and Donna also described how valuable the drop-in center had been for them. Both women acknowledged that the staff had been helpful in aiding socialization and developing relationships with other members of the drop-in center. Joy indicated that accessing the center had been pivotal in helping her through the days she struggled with her mental illness. This has been especially important for her well-being, because before she became familiar with the center she was

> very lonely, very isolated. Like, I still don't go out a lot, but I know the drop-in center is here, and I phone here and stuff, so I am in touch with people all the time, whereas before . . . there was nobody.

Inattentive and un-supportive physicians were the most commonly identified negative aspect of community treatment. This was perceived as minimizing the severity of experienced symptoms which often resulted in ineffective treatments. Frequently, the participants attempted to find a more attentive physician. Positive characteristics of community treatment included professionals who spent time with their clients, listened to them, and provided support and kindness. It was described as beneficial due to increased socialization and receiving appropriate treatment that enhanced functioning.

Diagnosis Education

Four participants did not recall having received information regarding their condition following diagnosis while hospitalized. They affirmed that the focus of hospitalization was on treatment and management of symptomology versus diagnosis education. Consequently, once discharged the participants independently educated themselves by accessing information through various resources such as mental health services, physicians, and the Internet. One participant was educated by hospital staff; however, he denied his diagnosis and therefore disregarded the information.

Donna did not receive diagnosis education while hospitalized and stated that she

> read a lot about it when I got out of the hospital, on my own. I knew a little bit about it, but I had a girlfriend who just got diagnosed, so she had a lot of information, and she went on the Internet and got a lot more information for me.

Similarly, Fred also relied on someone for assistance in obtaining diagnosis information. He stated that he wanted to understand what schizophrenia was and how it was going to affect his life. Consequently, Fred's sister helped access information through the library. Unlike Fred and Donna, Joy and Nina did not have assistance in accessing information. Consequently, Nina educated herself by accessing information through various resources such as mental health services and her physician. Similarly, Joy stated, "I am learning more about it; like, each time I go [to the doctor] I have more questions. When I think of something, I will write it down and I will phone my doctor and ask him."

The participants indicated that lack of information while hospitalized contributed to fears of mental illness and hospitalization. Nina therefore identified diagnosis education as an area in need of improvement and stated that hospital staff should educate patients about their diagnosis because "they need to know more about management and medications. They need to know more about maintaining stability and educating them about what their triggers are and how to recognize them."

Donna added that in addition to diagnosis education, information regarding community resources and services is needed upon discharge. Specifically, she stated:

> There needs to be a kit . . . that tells you where all this help can come from, a little card for mental health and their address and phone number, crisis line number, all the things you need that is out there for the support system and for the family that is now going to be dealing with you.

In contrast, Jim indicated that he received information upon diagnosis; however, due to his existing fears and perceptions of mental illness he denied his diagnosis and was disinterested in education. Jim indicated that he wanted to be discharged in order to return to normal life. A few years after discharge, Jim accepted his condition and educated himself to increase his understanding of his illness. However while he was hospitalized, his lack of diagnosis education compounded his existing fears. He stated:

> It was so frightening because of what I used to think it was and having to go through the process of learning what it really is. Then it was half the battle once you knew what it really was, a chemical imbalance. It is not that you are just crazy; it is just that some people have good chemistry in their bodies and some people are short of things. It was not as frightening once I was aware of what it was about.

Four participants were responsible for their own diagnosis education once discharged. They relayed not being provided with diagnosis information while receiving treatment in a psychiatric hospital. This lack of information sometimes resulted in compounded fears of mental illness. However, one participant received diagnosis education and relayed disinterest in the information because he was in denial of his diagnosis. In addition, the importance of education and suggestions to enhance access to community resources were discussed.

Impact of Diagnosis

Impact on Self

The participants shared the personal impact of being diagnosed with a mental illness. Positive impacts were experienced that enhanced functioning. However, following diagnosis and treatment, some participants experienced difficulty with accepting a mental illness diagnosis. Stigma, personal fears, and lack of diagnosis knowledge contributed to denial of diagnosis.

Jim indicated that once diagnosed, he was disinterested in his condition because he denied the accuracy of his mental illness diagnosis. However, a few years later, Jim accepted his diagnosis and recalled becoming a more understanding individual. Specifically, he stated:

> It has helped me be more understanding of others, especially who have a mental illness, whereas before I thought that I was healthier. But now I think that a person is healthier . . . when you understand other people's hurts. Before then you are so self-centered, but once you have the illness you become more understanding of others' suffering.

Joy also relayed a positive outcome to diagnosis. She stated that diagnosis "was almost a kind of relief to me because I knew I was not crazy, so it was kind of a relief because I knew that there was a valid reason for the way I think and act sometimes."

In addition, Joy stated that diagnosis led to accessing appropriate treatment and discontinuing self-medication with alcohol and drugs. Joy did not provide further information regarding her use of alcohol and drugs.

Similarly, Nina stated that diagnosis provided validation for what she had been experiencing. Also, once she accessed diagnosis information, it increased her awareness of signs and symptoms of her illness. However, she also indicated that initially she was angry at her diagnosis because she did not want to have a mental illness. Nina stated:

> It is part of the stigma. . . . I don't want to have a mental illness. But I have learned to accept it. I have learned to understand my triggers . . . and do something about them. If I don't, I'll just end up getting really sick.

In contrast, Donna reported that her condition had negatively impacted her life. Specifically, her illness affected her children, who have fears of inheriting a mental illness. Unfortunately, Donna did not elaborate on how this awareness had personally affected her or how she addressed the fears of her children. Fred was unable to identify being personally affected by his diagnosis.

Information provided in the interviews suggests that some individuals struggled with accepting their conditions. However, acceptance of diagnoses often resulted in accessing information and treatment. Other positive impacts of diagnosis included being more understanding of others and illness, being less self-centered, and accessing appropriate treatment. One identified negative family impact as fears of inheriting a mental illness.

Social Impact

In addition to the personal impact, the participants were also affected by the reactions of their family and friends, which included rejection, stigma, and support. The loss of family and friends varied from minimal to major loss, resulting in fewer supports during an already stressful time. The exception was Donna, who reported receiving constant support from family and friends.

Jim indicated that as a result of sharing his diagnosis, many individuals in his life were no longer as close to him as they once were. He stated, "It was quite overwhelming; it was very scary. A lot of people pulled away, and then you found out who your real friends were."

Joy also reported experiencing loss of family and mentioned the tension that exists between her and her brother as a result of his misunderstandings of mental illness. Furthermore, she recalled being deeply hurt. She added that they no longer communicated with one another. In addition, Joy also indicated that she has been affected by rejection and stigma in the community. Specifically, she shared that there is "one woman that does not want her child around me. I don't know why; I don't hurt kids."

Joy stated that the comments made by this woman have been hurtful and have reinforced her belief that she should keep her difficulties private to avoid further social rejection. Joy related that she deals with the rejection by trying to remind herself that

> she doesn't know me, and if she got to know me she would know that I was a good person. So she is the one that is losing out, not me. I try to tell myself that anyway, but it still hurts. Some people think that I am just a crazy lady, which is okay. I kind of take it one day at a time.

Unlike the other participants, Nina anticipated her family's negative reaction to her diagnosis and decided not to disclose her condition. She stated:

> I did not want to tell my family because they would flip out. So I just kept it to myself, and I did not tell anyone what was going on with me. I just kept it to myself and stuffed it.

Nina's decision not to disclose her diagnosis resulted in her having less support and having to falsely portray herself as a healthy and happy individual. Nina indicated that she was afraid of her family's reaction because they would make judgments and wrong assumptions about why she had been hospitalized and what she was experiencing. Her aunt eventually found out that Nina was slashing and shared this information with the rest of the family. She was "pissed off because I had no intention of them ever finding out. I knew that they would think that they could run my life better than me."

After many years of being admitted and discharged from hospitals, Nina's family has accepted her condition which resulted in their being more supportive and understanding. Fred reported a different experience as he shared his concerns regarding the symptoms that he was experiencing. However, his family denied the severity of his difficulties and Fred was left feeling alone not knowing where to access assistance.

In contrast, Donna shared a very different experience from those of the other participants. She stated:

> Nothing changed for me; I was very lucky. There is usually something that you are confronted with like divorce or your uncle not wanting to talk to you any more. I've never had that experience. As soon as something like that happens to you, you have to deal with that on top of getting well, on top of learning about your illness, on top of the whole nine yards.

Donna reported feeling grateful because she did not experience any loss of support in her life as a result of her illness. She indicated that she was aware of individuals who have experienced loss of social support and then struggled with symptoms due to the added stress of rejection and isolation.

Most participants relayed being adversely affected by sharing their mental illness diagnosis with others. The interviews indicate that negative family impact resulted in loss of support, lack of understanding, and judgments based on stereotypes. However, one participant described receiving family support while struggling with her condition.

Recovery

The participants were asked to relay their perceptions, opinions, and experiences of recovery. Interestingly, during the interview the participants required more time to formulate their thoughts and experiences about recovery in comparison to other topics. As is demonstrated, the participants described components of recovery without recognition that they were actively engaging in the process.

A common belief endorsed by the participants included recovery being achieved once medication was no longer required to treat the symptoms of their illness. Consequently, each believed that recovery is synonymous with no longer being affected by a mental illness. Most participants reported that mental health professionals providing treatment solely addressed the need for lifelong medication compliance.

Nina stated that she was educated only about management of mental illness. She stated, "The psychiatrist at the hospital just said that I needed to be on medication and that was it. The psychologist at mental health services also said that it could be managed by medication."

Similarly, Fred and Jim indicated that they would require lifelong medication and therefore they would never recover. However, Fred indicated some hope of no longer being affected by a mental illness. He stated, "Sometimes when I am on the pills I want to see what would happen if I would stop taking them." However, he added that he remains compliant with medication because he believes that there is no cure for schizophrenia.

In contrast, Joy stated that both her mental health worker and physician have often addressed recovery and remarked on improvements with her condition. Despite their hopes, Joy remained hesitant about accepting the possibility of recovery. She stated that her belief

> depends on how I am doing that day. Some days I say okay and some days I just disagree. And so there are days that I feel that I am never going to be okay, and there are other days I think, Hey, I am not too bad today.

Similarly, Donna endorsed her belief in the recovery process and identified the key factor in her recovery process. Donna stated that

> number one, you have to have purpose to get up in the morning. If you can only do two hours or four hours of work, work. If I was to stay at home I would be depressed, and then I would be back in the psychiatric hospital.

Despite the participants' restricted knowledge of recovery, they identified engaging in various activities to maintain a fulfilling life. Specifically, Nina stated that in order to stay well she reads, maintains her home, participates in the drop-in center activities, and spends time with her family. In addition, Jim indicated that participation in various activities at home has helped him to feel better. He stated, "My wife is there after work, . . . and we have a little garden. Those things help to get over things. It is much better than being in a hospital." Lastly, Joy indicated that medication compliance and talking about issues that were bothering her enhanced her sense of well-being.

The participants indicated that their beliefs of recovery were based on the belief that recovery could not happen with lifelong medication compliance. Despite this, the interviews indicated that the participants were cognizant of what was required to enhance their mental health because they were engaging in various activities that included accessing therapy, taking medication, being employed, engaging in meaningful activities, maintaining a home, reading, addressing personal needs, and participating in activities at the mental health drop-in center. These activities facilitated their wellness despite perceptions of lifelong illness.

CHAPTER SIX

DISCUSSION

In this chapter a discussion of the findings is presented and organized according to themes. In addition, an exploration of implications for the mental health system and professionals providing services to individuals diagnosed with a mental illness is discussed. The limitations of this research and suggestions for future research are also examined.

Treatment Experiences

Fears of Hospitalization

The participants described feeling fearful prior to hospitalization as a result of negative perceptions of mental health from media portrayals of mental illness. This finding was consistent with the research literature that indicated that individuals with a mental illness are generally aware of the negative stereotypes associated with mental illness and reports of the need to dispel myths of mental illness (Acuff, 2000; Conrad & Schneider, 1992; Thoits, 1985). The general feeling described by the participants highlights the importance of addressing misconceptions of mental illness. Possible impact of dispelling myths may include increased access to mental health services prior to condition deterioration. However, the results indicate that fears may not be easily addressed because they may also involve reevaluation of one's self-concept and future goals. Therefore efforts at education may somewhat alleviate the problem but would likely not completely address it because of the complex personal processes related to a mental illness diagnosis.

Hospitalization

The five participants of this study were hospitalized for mental health issues and concerns. Four participants relayed generally positive hospital experiences. They characterized the hospital staff as empathetic and supportive. These findings were consistent with research indicating that patient satisfaction is generally positive (Glass & Arnkoff, 2000; Lehman & Zastoway, 1983; Pickett et al., 1995). Commonality of experience suggested that psychiatric hospital staff are attentive to client needs, which enhances hospitalization experiences and possibly dispels negative perceptions and fears of psychiatric treatment facilities. Implications of positive treatment experiences include individuals feeling comfortable and re-accessing services when needed. This finding was contrary to research indicating the negative impacts that individuals experience as a result of societal stereotypes and stigma associated with a mental illness (Hatfield & Lefley, 1993; O'Reilley, 2001; Thoits, 1985).

Perhaps more qualitative research is needed to further explore the hospitalization experiences of affected individuals because research in this area is predominantly quantitative, thus providing little description. Also, previous research in the areas of stigma and labeling generally indicate negative impacts as a result of hospitalization and diagnosis. However, recent literature in the area of recovery has indicated many positive outcomes associated with treatment (Glass & Arnkoff, 2000).

The negative experiences of these participants predominantly included being unable to identify with the severity of difficulties of other patients. This may have been a result of attempts to maintain a sense of wellness as the research indicates that individuals attempt to maintain a positive self-concept by describing their own difficulties as less severe (Lally, 1989; Townsend & Rakfeldt, 1985). Participant experiences clearly illustrate this concept because they recalled feeling a sense of being different from other patients and feeling unsafe around them.

Interestingly, the participants did not recall developing friendships with other patients during any of their hospitalizations. Instead, other patients were characterized as being frightening, resulting in concern for personal safety. However, the participants recalled receiving support and encouragement from staff. This finding suggests that positive interactions were experienced; however, they were associated with staff and not with other patients.

The research indicated that lack of identification with other individuals with a mental illness results from the stigma associated with a diagnosis (Davidson & Strauss, 1992; Lally, 1989; Townsend & Rakfeldt, 1985). Specifically, lack of identification with others would decrease the extent to which an individual would personally or socially be perceived as having mental health difficulties. Perhaps the perception is that lack of identification would decrease association with diagnosed individuals and therefore reduce the possibility of stigma and rejection by others. Lack of identification may also postpone self-acceptance of one's own condition. Unfortunately, there was no verification of whether the participants' conditions were indeed less severe than those of others or whether these participants were de-emphasizing the severity of their conditions.

The findings emphasize the importance of addressing misconceptions and stereotypes of mental illness (Acuff, 2000; Conrad & Schneider, 1992) in order for individuals to access and receive appropriate treatment. Education may reduce the degree to which diagnosed individuals deny their experiences and facilitate their receiving support from both mental health professionals and other diagnosed individuals. Reducing the element of shame may also enhance self-acceptance and therefore daily functioning through gaining access to needed supports and services. Denial of the condition may also need to be addressed during hospital treatment or community out-patient services. Addressing denial may facilitate recovery by aiding acceptance of the condition and facilitate discussion of both negative and positive aspects of diagnosis. Overall, both positive and negative experiences were recalled which is contrary to the generally positive evaluations of hospitalization in the patient satisfaction literature (Lehman & Zastoway, 1983; Pickett et al., 1995; Pickett et al., 1995). However, negative experiences were consistent with personal narratives in the recovery literature (see Bassman, 2000; Everett, 2000; Lovejoy, 1982; Lynch, 2000).

Diagnosis Education

Related to treatment is participant diagnosis education. Four participants did not receive diagnosis education while hospitalized. Instead, they independently learned about their conditions by accessing information through mental health services, doctors, the Internet, the drop-in center, and public libraries. Lack of accurate information could potentially impact an individual because it may contribute to denial of the condition due to perceived stigma. However, denial may not be a result of stigma and may be attributed to being diagnosed with an illness regardless of whether it is a physical or mental illness. Regardless, denial of diagnosis may negatively impact individuals due to possibly not sharing diagnosis with friends and family to receive support, noncompliance with medication, and negative effects on one's self-concept.

The participants indicated that during various hospitalizations the focus was directed at effective medication rather than diagnosis education. As a result, individuals were admitted and discharged from a psychiatric hospital without understanding the nature of their condition. Perhaps the focus of treatment is due to limited staff resources that are not conducive to time allocations needed to educate patients. In addition the role of hospitals may not include diagnosis education and instead may be solely medical treatment. Even if the participants had received diagnosis education, they may not have comprehended the information due to existing symptoms, adjustment to medication, the stress of hospitalization or denial of condition.

Therefore, the role of community professionals such as mental health therapists, doctors, and counsellors may be in providing diagnosis information. Perhaps when clients access these services, providers could address diagnosis education instead of assuming that an individual is knowledgeable about his/her condition. In addition, prior to discharge, hospital staff could potentially provide patients with information and address concerns or questions to enhance understanding and reduce fears. Providing patients with a list of community resources specifying phone numbers for agencies such as mental health services, local drop-in centers, and Social Services for income support may also be useful.

Community Treatment Experiences

Similar to the hospitalization experiences, the participants identified both positive and negative experiences of community services. The participants who were discontent with service providers accessed different professionals to meet their personal needs and expectations. These participants described feeling unheard and minimized, which left them doubting themselves. Consistent with these results are the findings of the California Well-Being Project, which indicated that individuals accessing mental health services generally felt unheard (Hatfield & Lefley, 1993). This highlights the importance of professionals being attentive to client needs and concerns to ensure client trust, satisfaction, and appropriate treatment as these characteristics have been identified as being helpful in treatment (Glass & Arnkoff, 2000).

In contrast, one participant described her doctor as being attentive to her experiences and collaborating with her to find an effective treatment. Furthermore, she was pleased with her treatment and characterized her doctor as caring and attentive. This finding was characteristic of the mental health care satisfaction literature (Glass & Arnkoff, 2000; Lehman & Zastoway, 1983; Pickett et al., 1995).

Contrasting findings between the participants may have been a result of the familiarity of the doctor with mental health issues and treatment. Certainly, a doctor without experience and knowledge in this area would be more likely to overlook, dismiss, or minimize mental health concerns. Also, the relationship between the participants and their doctors was not explored, and therefore negative experiences may have been a result of not having developed a long-term relationship with them. Professionals need to be attentive to client needs and concerns. A professional may be the only individual whom the client accesses for treatment and support.

Positive experiences included the participants' unanimously identifying the community drop-in center as a source of acceptance and support. The drop-in center was characterized as an important part of dealing with the stigma and isolation associated with a mental illness. In addition, it was described as a place that enhanced socialization. Although the drop-in center was not identified as a place to access specified treatment, it certainly was discussed as an important means of dealing with the many implications of mental illness. This finding was not surprising given the literature that indicated the value of supportive individuals of a person with mental illness (Acuff, 2000; Anthony, 1993; Ridgway, 2001).

Impact on Self

The research literature indicated that individuals with a mental illness will be personally impacted by diagnosis (Conrad & Schneider, 1992; Davidson & Strauss, 1992; Hatfield & Lefley, 1993; Townsend & Rakfeldt, 1985). In this study, four participants indicated that diagnosis of a mental illness had personally impacted them both positively and negatively. However, one stated that his diagnosis had not impacted his life in any manner.

Following diagnosis, the participants experienced difficulty in accepting their condition. This is consistent with the research findings indicating that diagnosed individuals generally know that their condition is undesirable (Conrad & Schneider, 1992). More specifically, participant denial was a result of misperceptions of mental illness and fears associated with having a mental illness.

However, being diagnosed resulted in accessing appropriate treatment that positively impacted functioning. Other impacts of diagnosis included being less self-centered and more understanding, and no longer self-medicating.

The participants experiences indicate that the personal impact of diagnosis was generally positive. This is contrary to research that suggested that individuals are attentive to negative perceptions of mental illness and incorporate these perceptions into their self-concept (Hastorf & Isen, 1982; Kelly, 1955; Lally, 1989). It is important not to assume that individuals with a mental illness will be negatively impacted by diagnosis. This type of assumption may influence expectations of stigma, enhance fears of being diagnosed, and decrease access of mental health services. Professionals could focus on the positive impacts of diagnosis such as treatment of symptoms, which results in enhancement of daily functioning. In addition, discussion of recovery and personally meaningful ways to enhance functioning would also be helpful.

Social Impact

Four participants indicated negative social impact of diagnosis. Some participant experiences illustrate the fact that individuals with a mental illness commonly lose their families (O'Reilley, 2001). The stress of dealing with mental illness often leads to families severing relationships with the individual affected (O'Reilley, 2001), which was evident in this study. In addition, social rejection because of diagnosis has also been identified in research (Rubin & Fink, 1992; Hayward & Bright, 1997) and was identified by one participant.

The role of counselors and mental health therapists may be in addressing concerns with affected individuals and strategies for coping with family members in an attempt to reduce the possibility of abandonment. The literature indicated the pervasive nature of societal misperceptions and stereotypes of mental illness (Conrad & Schneider, 1992; Rubin & Fink, 1992), and the role of professionals may be to address these perceptions by providing diagnosis information to both the affected individuals and their families. In addition, providing support to families would be an important aspect in enhancing the support systems of diagnosed individuals. The positive experiences of one participant serve as a reminder that not all families and friends will abandon a member with mental illness.

Recovery

Once diagnosed, many individuals engage in the process of recovery to enhance functioning. The interviews suggested active participation in various activities that enhanced functioning without acknowledging engagement in the recovery process. Reported activities included accessing therapy, reading, working, spending time with family, accessing support from the drop-in center, and gardening. These types of activities have been identified in the research literature as being indicative of the recovery process (Jacobson, 2001; Leete, 1988; Ridgway, 2001).

Overall, the participants indicated a belief that recovery entails no longer requiring medical treatment. This finding was consistent with the literature that indicated that recovery is a fairly new concept, challenging the predominant medical model that has historically overlooked recovery of a mental illness (Anthony, 1993). This belief may be a result of professionals addressing long-term medical treatment versus a recovery prognosis. The participants relayed the belief that medication compliance excludes the possibility of recovery. This belief has been identified in the literature as a result of the recent emphasis on self-management, which emphasizes reducing medication utilization to minimal levels; consequently, individuals unable to reduce medication levels may view themselves as failures (Jacobson, 2001). However, the results of this study indicate that the participants did not view themselves as failures, but rather as not recovered. In addition, their perceptions of recovery may be influenced by the use of the term with physical illness.

The results of this study suggest these individuals had generally not been educated about recovery and instead believe that they have a chronic disability. This may be a result of utilization of different terminology as the participants indicated that they were engaging in various activities to enhance functioning that were indicative of the recovery process. Participant beliefs regarding recovery suggest that that recovery was not possible while taking medication for symptom management. Perhaps the utilization of the term *recovery* paired with education of the recovery process would promote participation in activities that enhance functioning. Furthermore, the hope facilitated from such discussion may reduce adjustment to lifelong disability by encouraging participation in activities that enhance a sense of well-being. The role of professionals could be to focus on the strengths of these individuals instead of focusing on assumed long-term limitations typically associated with a mental illness. This is not to say that realistic limitations should not be identified and addressed; however, achievable goals could also be stressed. The result may be potentially fewer individuals submitting to expectations of chronic disability.

Limitations

The purpose of this research project was to explore the experiences of individuals affected by mental illness in regards to treatment, diagnosis education, referral to community resources, stigma, and recovery. Qualitative methodology, specifically the use of purposive sampling and in-depth semi-structured interviews, was used to collect data for this research study. Limitations of this type of methodology include the possibility of non-representativeness of the sample because individuals who volunteered may be extraordinary individuals or may have experienced contact with the mental health system in a different manner than average individuals have.

In addition, I am familiar with many individuals who frequently access the drop-in center as a result of a previous research study. Therefore the possibility exists that certain individuals may not have volunteered because of our acquaintance. Similarly, individuals who volunteered for this study may have participated because of their familiarity with me, their perceptions of the benefits of participating in the study, or the nature of their experiences. Furthermore, personal experiences may have been edited or altered in order to present in a manner consistent with their perceived expectations of the intent of this research.

In addition, interview questions were focused on past events, and as such recollections may have been inaccurate due to lapse of memory and mental health status during and following hospitalization and during the interview. Nevertheless, the participants provided detailed information regarding their experiences, feelings, and thoughts and provided insight into the issues they faced.

Lastly, the scope of this study was inclusive of many issues related to mental illness. The variety of topics may have reduced the amount of detailed descriptions relayed in the interviews. Because of the complexity of these issues, future research may benefit from focusing on a specific area to provide more detailed information.

Implications for Research

As research in the area of mental illness has historically addressed treatment efficacy studies, current research addressing the experiences of individuals affected by a mental illness is needed. Current information would provide useful insight into the types of treatment interventions and resources that would best address the physical, emotional, and social issues faced by these individuals.

Research from the previous two decades has provided the basis for perceptions and assumptions of mental illness, hospital experiences, and the impact of diagnosis that may inaccurately portray current attitudes and beliefs. Research addressing these areas is essential in planning appropriate and effective interventions that may affect the global functioning of these individuals.

In addition, future research directly impacts government allocation of financial resources and the development of services. Therefore, research addressing the experiences of individuals affected by mental illness, societal attitudes towards mental illness, and evaluations by mental health service providers is vital to strengthening the mental health system.

Conclusion

This research study was intended to provide a medium through which to voice the experiences of individuals diagnosed with a mental illness because of the limited research that has been conducted in this area. The participants of this study discussed personal experiences that enhanced insight regarding the experiences of affected individuals. The results of this study indicated fears of hospitalization, positive and negative treatment experiences and impacts of diagnosis, restricted knowledge of recovery, and lack of diagnosis education while hospitalized. Positive experiences included accessing appropriate treatment, enhanced functioning, personality improvements, and forming supportive relationships with other individuals with a mental illness. However, negative experiences included having mental health concerns minimized, poor hospitalization experiences, and experiencing rejection and stigma. The findings of this research indicate that the topics discussed were complex; participant experiences varied and highlighted many issues that require further investigation.

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APPENDIX A: PARTICIPANT POSTER

Research Study Overview

In order to participate in this study you must be legally competent and 18 years of age. Participation in this study will include being asked to share the following with the researcher: your experience of the diagnostic and treatment process, the nature and extent of your involvement in your treatment plan, whether or not treatment alternatives were presented to you, whether or not you were educated about your illness, if you were referred to community services/programs for outpatient support, and your personal adjustment process to your mental illness diagnosis.

Participant Criteria:

1. Participants will be 18-50 years of age
2. Psychiatric diagnosis by either a medical doctor or psychiatrist
3. Currently taking medication to treat a mental illness and under the care of either a medical doctor or psychiatrist
4. Have been hospitalized for a mental illness
5. Have been out of the hospital for at least 6 months

If you meet all the criteria listed above and would like to volunteer to take part in this research project, please contact Jas Badesha at 352-4979. If no one is there to take your call please feel free to leave a message.

APPENDIX B: RESEARCH OVERVIEW

Mental Illness Research Project
Researcher: Jaswinder Badesha (780-352-4979)
Research Supervisor: Dr. Robin Everall (780-492-1163)
University of Alberta

The purpose of this research project is to explore the experience of individuals affected by mental illness. In order to participate in this study you must be legally competent and 18 years of age. Participation in this study will include being asked to share the following with the researcher: your experience of the diagnostic and treatment process, the nature and extent of your involvement in your treatment plan, whether or not treatment alternatives were presented to you, whether or not you were educated about your illness, if you were referred to community services/programs for outpatient support, and your personal adjustment process to your mental illness diagnosis. The interview will be completed in one, maybe two, one-hour interviews, scheduled at a time that is convenient for you. The interview will be audio taped and later transcribed. Your anonymity and confidentiality will be protected through the use of pseudonyms and alteration of any personally identifiable information. If you have any questions or concerns regarding this research study, please feel free to contact either Jaswinder Badesha or Dr. Robin Everall.

APPENDIX C: CONSENT FORM

Department of Educational Psychology
1-135 Education North
University of Alberta

Researcher: Jaswinder Badesha (780-352-4979)
Research Supervisor: Dr. Robin Everall (780-492-1163)

The purpose of this study is to explore the experiences of individuals who have been diagnosed with a mental illness. More specifically, the experiences of individuals who have been affected by a mental illness in relation to the diagnostic and treatment process, as well as the personal adjustment process following the diagnosis of a mental illness will be explored in depth. Information gathered in this research project may provide mental health professionals with in-depth information of the experiences of individuals that have been affected by mental illness. It is hoped that the results of this study may influence future outpatient community program planning and resources for out-patients.

In an interview, I understand that I will be asked to verbally share my experiences of the diagnostic and treatment process within the mental health system, as well as my adjustment process as an outpatient. I understand that this is a voluntary project, and that in order to participate in this study I must be legally competent. I also understand that I have the right to withdraw my participation from this study at any time, without prejudice, and that my right to confidentiality and anonymity will be protected through the use of pseudonyms and alteration of any personally identifying information. The individual interview is anticipated to be completed in one, possibly two scheduled meetings, lasting approximately one hour each. This interview can be completed at a time that is convenient for me. The interview will be audio taped and transcribed. Upon request, a copy of the completed research study will be provided to me.

I have an understanding of:

1) the purpose and nature of the project,
2) the expected benefits,
3) the tasks involved,
4) the inconveniences and risks, the identity of those involved in the project
5) who will receive the information
6) how the information will be used

7) the right to give or withhold consent for participation,
8) the right to withdraw at any time during the process,
9) how confidentiality will be maintained.

I give my informed consent to participate in this project.

_________________________	_________________________
Date	Name of Participant
_________________________	_________________________
Signature of Researcher	Signature of Participant

APPENDIX D: SAMPLE INTERVIEW QUESTIONS

Mental Illness Research Project
Jaswinder Badesha

1. What was your experience of being diagnosed? Where were you diagnosed, and by whom were you diagnosed?
2. Were you educated about your illness? If yes, then by whom? If no, then how did your learn more information about your illness?
3. Were you connected to community agencies/programs/AISH after your diagnosis by mental health workers? If yes, by whom? If no, how did you find out about community agencies/programs/AISH?
4. Did your life change as a result of the diagnosis? If yes, then how?
5. Did your mental illness diagnosis have an impact on how you saw yourself? If so, then how?
6. What information did you not know during the process that you would like others to know that are just beginning contact with mental health system?
7. Is there anything else that you think that I need to know?