The Meaning of Education for University Students with Mental Illness: 
An Exploratory Qualitative Study

by

Enid Weiner

A thesis submitted in conformity with the requirements 
for the degree Doctor of Education

Graduate Department of Applied Psychology and Human Development
University of Toronto

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HE WHO HAS THE WHY TO LIVE CAN BEAR WITH ALMOST ANY HOW.

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The Meaning of Education for University Students with Mental Illness: An exploratory qualitative study.

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Enid Weiner

Graduate Department of Applied Psychology and Human Development

University of Toronto

ABSTRACT

With the development of services for students with disabilities at post-secondary educational institutions, students with mental illness are self-identifying in increasing numbers. Given the recent emergence of this particular student sub-group, there is a paucity of literature in the area. The few studies that have been conducted emphasize needs assessments and the identification of academic accommodations required, while briefly discussing the unpredictable nature of mental illness and the frequent interruptions they cause to these students' learning. Although post-secondary educational models of learning have been developed to serve this population, no one has explored the meaning of their education and what they hope to accomplish in their educational pursuits.

In this qualitative study, eight university students with mental illness, who were attending a large campus, were interviewed, in-depth, in order to explore the purpose and goals of their academic program. Three groupings emerged: students who saw university as a means to an end, part of a larger life goal; students who saw university as an end in itself, their primary life goal at the present time; and those students who, because of the precariousness of their illnesses at the time of the study, were situated in between these two groupings. The results also indicated that the illness
and the university experience of these students are intertwined. The trajectory of the illness, its fluctuating course, its stigma, how the students managed their illness, and the support systems in place for them, all affected how they functioned on campus in the student role, both academically and socially.

Although the participants shared similar educational goals to the general population of students, they viewed their social and emotional stresses as qualitatively different. Thus, the nature of their illness meant having to complete their studies over a longer period of time, although they felt they were just as intelligent as the rest of the student body.

Educational policies and procedures that allow, not only greater access to institutions of higher learning, but flexibility around these students' pace of learning, provide a critical backdrop by which to understand their integration into mainstream campus life. These educational practices, combined with the support of family, friends and professionals in the community, played a vital role in the students' experiences. Despite the importance of the structure it gave to their lives, the normalizing experience and a strong sense of hope that attending university provided, the participants all agreed that their mental health took priority over completing their education.
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CHAPTER 1
INTRODUCTION

Purpose

Until recently, there was little research into first person experiences of individuals with psychiatric illnesses (Hatfield & Lefley, 1987, 1993; Lefley & Johnson, 1990). A biomedical emphasis dominated many of the investigations (Cohen, 1993; Shore & Keith, 1991). Currently, there is an increasing trend in psychiatric research to explore the subjective experiences of persons with mental illness (e.g., Boydell, Morrell-Bellai, & Gladstone, 1993; Everett & Boydell, 1994). As the mental health system redefines its mandate (Ontario Ministry of Health, 1993; Trainor, Pomeroy, & Pape, 1993) and consumers play a greater role in their treatment programs, researchers have begun to give more recognition to their lived experiences (Estroff, 1981, 1989; Strauss, 1989). The focus of this study will be the exploration of one dimension of that subjective experience: the meaning of university education for students living with a serious mental illness.

In the literature in higher education, students with mental illness are often referred to as students with psychiatric disabilities. These terms will be used interchangeably in this study. Whatever their origins (biologically or psychologically based), mental illness or psychiatric disabilities are considered to be impairments of prolonged duration that affect a person’s functional abilities in most spheres of life (Anthony, Kennard, O’Brien, & Forbess, 1986).

The definition of mental illness or a mental disorder in the Diagnostic and Statistical Manual of Mental Disorders -IV- R (1994) is as follows:

...a clinically significant behavioral or psychological syndrome or pattern that occurs in an individual and that is associated with present distress (e.g., a painful symptom) or disability (i.e., impairment in one or more important areas of functioning) or with
a significantly increased risk of suffering death, pain, disability, or an important loss of freedom (pp. xxii).

The onset of many mental illnesses takes place during adolescence or early adulthood. Gelder, Gath and Mayou (1996) indicate that schizophrenia is generally first experienced in the late teens or early twenties. Obsessive compulsive disorders often are present in childhood (Rapoport, 1989), although they may not be recognized as such until the teen years or early twenties. At this stage in their lives, young adults may be considering a university program. Perhaps they are in their freshman year or even in the middle of their studies. The onset of mental illness, therefore, may result in interruptions to their educational plans.

Although higher education provides opportunities for students with psychiatric disabilities to reintegrate into mainstream society and to assume meaningful roles, there is still a stigma attached to the illness (e.g., Lyons & Hayes, 1992; Raty, 1990; Townsend, 1990; Wahl, 1987). Given this stigma, the often invisible nature and unpredictability of the illness, and the trajectories of both the illness and the student’s academic career, the educational experience of a student with a psychiatric disability may differ substantially from that of the general student population. My thesis will address two aspects of this difference: (a) the meaning that university education has for students with mental illness, and (b) whether a shift occurs in that meaning over time, and if so, why and how. Although I have had a good sense of the immediate goals and objectives of students with psychiatric disabilities as a result of my professional work in this area, I had never explored these issues in depth. I wanted to understand more fully the perception that students with mental illness have of their time at university and the expectations that they have of their academic pursuits. The findings of such an investigation can affect the kind of service delivery that is currently being
provided to these students and perhaps heighten the students' own awareness of their reasons for being at university.

**Phenomenological Interviewing: A Means of Investigating the Experiences of Students with Mental Illness**

Attinasi (1992) argues that research on post-secondary student outcomes falls short in understanding the meanings that the students attribute to their college education. For a researcher, one way of accessing the meaning of someone's experiences is through phenomenological interviewing (e.g., Bogdan & Biklen, 1992; Patton, 1991; Tesch, 1987, 1990). This approach is based on the premise that the researcher cannot come to know an individual's behaviour without understanding the unique meaning the person gives to his or her situation. Because of the exploratory nature of this study and because of the complexity of the processes being investigated, a qualitative methodology was chosen to present the experiences of the students involved.

Patton (1990) stresses the importance of the researcher's familiarity with the phenomena under study. My role as an educational advocate for university students with mental illness began almost seven years ago. Having spent a great deal of time with these students, I have often heard their personal stories. Some of them have made a huge leap from the patient role to the student role, from the hospital and community mental health environment to an educational environment that is academically and socially demanding. Many factors may contribute to the meaning that they attach to their education including the experiences of a long-term and unpredictable illness, of intermittent interruptions in their schooling, and the fact that they must follow a reduced course load. These circumstances increase the likelihood that students will take longer to complete their university program than they would under ordinary circumstances and thus further influence the meaning.
At present, students with mental illness remain a relatively unknown and untested population in terms of their successes or failures at university. Existing data and theory are inadequate to develop an understanding of how they may make a successful transition from a patient role to a student role, benefit optimally from university and achieve their personal goals.

The transition from home or work into the college and university environment is a highly complex one for all students. It has been described in the following words:

The nature and dynamics of the process vary according to the student's social, family and educational background; personality; educational and occupational orientations and aspirations; the nature and mission of the institution being attended; the kinds of peers, faculty and staff members encountered; the purpose and nature of the encounters, and the interactions of these variables. The process is a highly interrelated, web-like series of family, interpersonal, academic, and organizational pulls and pushes that shape student learning (broadly conceived) and persistence (Terenzini et al. 1993, p. 91).

Understanding of this complex process can be enhanced by the use of first person accounts by students who have experienced it.

Lincoln and Guba (1983) propose the case study report as a natural mode of inquiry for qualitative researchers. The case study format has been described (Denny, 1978, quoted in Lincoln & Guba 1983, p. 360) as an "intensive or complete examination of a facet or issue, or perhaps the events of a geographic setting over time." Case studies are intended to provide a more in-depth understanding of an investigator's findings. Stanovich (1992) discusses the role that case studies play in "opening up new areas of study" in research (p. 55). He also describes the limitations of case
studies as a basis for generalization, but regards them as a source of useful insight. Because I use in-depth personal accounts to present my own findings in this thesis. I shall discuss this method of investigation in greater detail in my literature review.

While each participant's personal story regarding the meaning of his or her university education is situated in the foreground of this study. I shall also consider the background. that is, educational policies and practices that also impact on these students’ experiences at university (e.g., the students’ perceptions of current procedures they must follow to request academic accommodations for a psychiatric disability). How do these educational practices intersect in the discussion? What ideologies in the educational community regarding mental illness help shape these practices, the students’ self-perceptions and the location of my own position in the study?

**Background**

**Psychiatric Rehabilitation**

The few specialized support programs for students with mental illness on college and university campuses are based on the philosophy and principles of psychiatric rehabilitation (Anthony, Cohen. & Farkas. 1990). This approach is founded on the belief that psychiatric diagnoses do not predict treatment outcome. Psychiatric rehabilitation was developed as a way of helping individuals with psychiatric illnesses to focus on their functional abilities and strengths rather than on their symptoms and their weaknesses. The goals of psychiatric rehabilitation are to increase the functioning of persons with mental disorders so they can be successful and satisfied in their environment of choice. with minimized on-going intervention (Anthony et al. 1990). The methods employed to achieve these goals include the provision of both appropriate skills and environmental supports in the rehabilitative environment. Community housing and employment
opportunities became the initial goals of service providers committed to providing rehabilitation (Unger, 1993). However, as service providers became aware of the importance of education to psychiatric rehabilitation, they began to develop programs to meet these needs. Only recently has higher education as a means to employment for persons with psychiatric disabilities been considered a viable option (Unger, 1993).

**Post-secondary Educational Services for Students with Disabilities**

Programs for students with disabilities on college campuses grew out of the field of special education where students with ‘special needs’ were first categorized. Public school students in Ontario are protected by legislation (1980, special amendments to the education act, commonly known as Bill ‘82). Chapter 19 (Section 1, Revised Statutes, 1990) of the Ontario Human Rights Code (See Appendix ‘A’) mandates the right to equal treatment with regards to goods, services and facilities for individuals with ‘handicaps’. However, the code does not set specific standards for its application. Without such standards, post-secondary students with mental illness are at increased risk, at a time when research is beginning to show that they are able to perform successfully providing they receive appropriate supports (Hoffmann & Mastrianni, 1989; Tutty, Belanger, & Gregory, 1993; Unger, Anthony, Sciarappa, & Rogers, 1987).

**Supported Education for Students with Psychiatric Disabilities**

There are a variety of ‘supported learning’ programs on post-secondary campuses to assist students with mental illness in their adjustment to the community of higher education. Supported education for students with psychiatric disabilities is a relatively new concept on college and university campuses. Between 1983 and 1988, The Center for Psychiatric Rehabilitation at Boston University, funded by a grant from the National Institute for Mental Health and the National Institute
for Disabilities Research and Rehabilitation, formulated three prototypes of supported education programs for adults with a history of mental illness: 'self-contained', 'mobile' and 'on-site' (Unger, 1992, 1993). In the 'self-contained' model, individuals recovering from a mental illness attend non-credit classes, typically on a college or university campus. Emphasis is placed on personal development, vocational planning and academic upgrading. Once completed, participants in 'self-contained' programs may move into a larger educational setting through a 'mobile' support team, or they may become involved with an independent 'on-site' program at the post-secondary institution of their choice. In the 'on-site' model, a staff person (or persons) designated by the institution provides support to students with psychiatric disabilities. All three models share a common goal - to help these students achieve access to higher education in a manner in which they can experience success. Cooper (1993) defines supported education as:

...education in integrated settings for individuals with severe psychiatric disabilities for whom postsecondary education has been interrupted or intermittent as a result of severe psychiatric disability, and who, because of their handicap, need ongoing support services to be successful in the educational environment (p. 26).

Dougherty, Hastie, Bernard, Broadhurst, and Marcus (1992) propose the expansion of clubhouse community programs (social/recreational programs for individuals with severe mental illness) to include college level and campus based educational programs for its members:

...education is part of our culture, a way of life, and a way of helping people to be what they can be - good citizens, good workers and good people. Education, therefore, ought to be available to everyone, including people with mental illness, to
allow them to explore and discover more about themselves and the world around
them (p. 97).

Researchers have evaluated the effectiveness of the 'self-contained' model (e.g. Tutty, Belanger, & Gregory. 1993; Unger, Danly, Kohn, & Hutchinson. 1991) and have found improvement in the students' self-image, interpersonal skills, as well as a reduction in the number of their hospitalizations. To date, no one has evaluated the effectiveness of 'mobile' or 'on-site' educational programs, or the appropriateness of the three models to specific student populations or circumstances.

Although the focus is on students with mental illness in this thesis, there are many respects in which their concerns do not differ significantly from those of the general student body. In the next chapter I shall present a review of the literature of both the goals and objectives of higher education for the general student population, as well as specific sub-groups. Attention will be placed on the sparse but current literature in the area of post-secondary education and students with psychiatric disabilities.
CHAPTER 2

LITERATURE REVIEW

Research of General Student Population

Quantitative Studies

Numerous quantitative studies have been conducted on students’ goals and objectives with regards to pursuing higher education (e.g., Burbach & Babbitt, 1988; Church & Gillingham, 1988; Clagett, 1989; Gonzenbach, 1993; Holdaway & Kelloway, 1987; Knight, 1990). Regardless of students’ cultural background, one very strong and consistently reported factor in their pursuit of a post-secondary degree has been the family’s influence, either directly through verbal encouragement and financial support, or indirectly, through the educational level and socioeconomic status of the parents (e.g., Cardoza, 1991; London, 1989; Rendon, 1992; Rumberger, 1983; Thomas, G., Alexander, K., & Eckland, B., 1979).

Other variables have been cited as influencing student objectives in pursuing higher education: desire for personal growth and development (e.g., Chickering, 1993; Hayden & Carpenter, 1990), social and academic development (e.g., Tinto, 1982, 1993), critical thinking skills (e.g., Browne & Keely, 1988; Pascarella, 1989), institutional goals and values (e.g., Tinto, 1975, 1982, 1993), self-motivation (e.g., Kraft, 1991; Terenzini et al, 1993), job and career advancement (e.g., Healy & Reilly, 1989; Holland & Eisenhart, 1988). The relative importance of these factors varies by study and depends on many other variables: sampling (e.g., age, ethnicity, gender, disability), geographic location (e.g., urban or rural), type of institution (e.g., two or four year program, residential and/or commuter) and measurement techniques (e.g., questionnaires, mailed surveys and open-ended interviews).
A preponderance of the studies of student goals for post-secondary education has dealt with community college students pursuing a two year degree. Most of the studies are quantitative and, as such, do not present individual experiences. Patton (1991) notes that this quantitative approach provides an overview of group performance rather than of individuals (p. 391). Large sample sizes are typically used to represent the general student population, and analyses are directed towards generalized, replicable findings rather than personal experiences and perceptions.

The most extensive quantitative work in the area of post-secondary student attrition has been done by Tinto (1975, 1982, 1987, 1993). He posited the notion that the academic and social integration of students into campus life was critical if they were to be successful in completing their education. In his view, whether the student chooses to remain or withdraw depends upon a complex series of interactions between the student and the institution (peers, faculty and administration). In his research, which is based on the traditional student population, he has developed an interactive model consisting of six key constructs: (a) background characteristics (i.e., individual attributes, family background and educational expectations), (b) initial degree of commitment to the particular educational institution (i.e., initial choice of institution), (c) academic and social integration (i.e., maintaining required academic standing, engaging in the formal and informal social systems through faculty and peer interactions), (d) subsequent commitment to the university (i.e., motivational level, commitment to completing one's education), and (e) retention/withdrawal rate.

Tinto (1975) began his investigations using a social integrationist perspective. His hypotheses were drawn from existing theories of Emile Durkheim (1951) and Arnold Van Gennep (1960). Durkheim (1951) claimed that the greater the degree to which a person integrated into the fabric of societal institutions, the less likely he or she was to experience rootlessness. Van Gennep
(1960) purported that all cultures have rites of passage that help to integrate its members through various stages of development. Tinto (1975) viewed integration into the community of post-secondary educational institutions as a kind of 'rite of passage' into the larger world, as if the world of higher education were a homogeneous one. His general theory of student participation has been increasingly criticized for its exclusion of racial and ethnic minority groups (e.g., Muguia, Padilla, & Pavel, 1991; Tierney, 1992). Tinto’s model was developed to explain the attrition of primarily white, middle class, residential, full-time students who began university immediately after secondary school. He agreed that it fell short in paying attention to the structural organization of the institution (e.g., size, type, policies) or to individual differences in student ethnicity, socio-economic status, sexual orientation, age, gender, full-time/part-time status and disability (Tinto, 1982, 1987, 1993).

Qualitative Studies

When the focus of research shifts to the experiences of specific sub-groups, not surprisingly, qualitative methods are more common. Qualitative studies in higher education have been conducted at four levels: at the institutional level (e.g., Arnold, Mares, & Calkins, 1986; Dietsche, 1990; Doll & Jacobs, 1988), at the program and service level (e.g., Beasley-Fielstein, 1986; Whitt, 1991), at the faculty, staff and student subgroups level (e.g., Benjamin et al. 1993; Wood, 1993) and at the individual level (e.g., Empire State College, 1984; Terenzini et al, 1993; Walleri & Peglow, 1988). A variety of qualitative methods have been used to access the information: for example, focus groups (e.g., Bers & Smith, 1988; Jalomo, 1995; Rendon, 1993), participant observation (e.g., Christman 1988; Wade, 1984), narratives (e.g., Cairns, 1994) and case studies (e.g., Marinelli, 1994; 1986; Meyers, 1985; Wren et al, 1987).
The qualitative approach differs in terms of its assumptions, goals and methods of data collection and analysis (Patton, 1991). The main purpose of qualitative research is understanding rather than generalizability (Guba & Lincoln, 1981). The smaller sample sizes result in more detailed information about the participants (Caple, 1991). One early qualitative study of law students' experiences during the first year of their program (Patton, 1968) laid the ground work for a more recent increase in qualitative research studies on college students (e.g., Creamer & Creamer, 1988; Kuh & Andreas, 1991; Kuh, Lyons, Larimore, & Haynes, 1991; MacKay & Schuh, 1991; Murguia et al. 1991; Scott, 1991; Whitt, 1991). This development appears to reflect the researchers' desire for a further understanding of students' personal experiences on college campuses and the complexities of the higher education environment.

Quantitative/Qualitative Studies

Some studies have combined a qualitative and a quantitative approach (e.g., Kinnick & Kemper, 1988; Polkosnik & Winston, 1989), allowing the investigators to identify both general and idiosyncratic patterns in the data. Kinnick and Kemper (1988) chose both a quantitative and a qualitative methodology as a means of developing a deeper understanding of factors involved in students achieving a bachelor's degree following a two year community college program. The authors interviewed students who had received a four year degree in order to gain "further understanding of the human meaning behind numbers" (p. 299). They discovered that having goals and high self-motivation were two important factors in the students' success.

Research of Non-traditional Student Population

Qualitative Studies

As an increasing number of students who do not fit the typical student profile appear on
college campuses. Researchers are using qualitative methods to gain an understanding of several of these groups including aboriginal students (e.g., Benjamin et al. 1993; Hampton, 1993; Steward, 1993; Te-Hennepe, 1993), ethno-culturally diverse students (e.g., DeBord & Millner, 1993; Kraft, 1991; Padilla & Pavel, 1994; Murguia et al., 1991), older students (e.g., Fleishman, 1992) and students with disabilities (e.g., Sheridan & Ammerati, 1991; Shessel, 1995; Weiner, 1996; Weiner & Wiener, in press).

Critical education theorists contend that educational institutions have established borders that are difficult for non-traditional students to cross (Giroux, 1992; McCarthy, 1990; Tierney, 1991; Valadez, 1993). For example, interviews with 18 Afro-American students (Davis, 1994) in predominantly white, two and four year colleges indicated that their sense of identity reflected their experiences of racial stereotyping and labelling by other students. Davis (1994) found several common themes. One was the importance of social interaction provided by black support groups, which functioned as "safe havens" from the experience of constant racism.

Kraft (1991) asked 43 black students to describe the basis of their academic success on a predominantly white campus. His findings enabled him to understand why some black students function better than others in that particular academic environment. In addition to family encouragement, he found that students' perceptions of faculty and peer attitudes played an important role in minority students' evaluations of their academic experiences. Results suggested two key factors as important for academic success: personal discipline (e.g., setting priorities, time management, organizational skills, motivational level) and some form of social support (e.g., faculty, peers and family). Support from faculty included accessibility, feedback on students' work and willingness to spend time with students. Personalized attention from faculty helped create a positive
environment in which the students felt they could ask for help without feeling that they were less intelligent than their peers. Peer support included an opportunity to study with other students. A closeness with their own cultural community on campus helped, in some instances, to reduce their sense of social isolation.

Results from qualitative studies can challenge the taken-for-granted assumptions about students' experiences on campus (Kuh & Andreas, 1991). For example, in interviews with 11 Native American students, Benjamin et al (1993) found that unlike students of European origins, for whom absenteeism is typically related to lack of motivation or other academic problems, the Native students often missed classes in order to go home to attend tribal ceremonies. An understanding of the priorities and "perceptions of the world" of Native culture that underlie this difference and others could enable the dominant culture to lower the barriers that it has raised before Native students.

Murguia et al (1991) explored the role that ethnicity plays in Tinto's (1987) interactive model of college students' social and academic integration into campus life. The authors' qualitative analysis helped expand the parameters of Tinto’s concept of social integration. Through open-ended interviews of 24 junior and senior Hispanic and American students at a large urban university, they ascertained that social integration does not necessarily occur at the campus level, but "within smaller subunits or enclaves" (p. 436) such as athletic groups, religious clubs and ethnic organizations.

...Once integrated into one or more enclaves, the rest of the campus simply becomes a backdrop that the student can explore what she or he desires or needs to do so...and provides a means for students to scale down the campus and integrate socially (p. 436).
In a qualitative study of Hispanic and American Indian college students’ use of academic advising, Padilla and Pavel (1994) found a relationship between students’ use of academic advising and their integration into academic dimensions of campus life. In their study, which examined individual students’ use of advising in depth, they found that “advisor comportment and the rapport established between the advisor and the advisee” (p. 155) appeared to be the key aspect of the advising process. The authors suggest that Tinto’s model of academic integration can be expanded by including both the content and process of academic advising.

One of the most thorough and comprehensive studies on individual differences regarding the transition to a variety of post-secondary educational settings was conducted by Terenzini et al (1993) in a series of focus interviews. The authors interviewed 132 students from a variety of backgrounds at their respective entries into a community college, a liberal arts college, an urban university and a large research university, asking them their hopes and reasons for attending an institute of higher learning. They reported that non-traditional students regarded the transition to post-secondary education as one of the most challenging events in their lives. Unlike the traditional students, they deferred involvement in extra-curricular activities until they had established a firm grasp on their academic studies. The authors also found that a number of non-traditional students entered the institution with considerable doubts and required ‘validation’ in order to feel supported. Validation meant feeling empowered and supported by significant others and was described as:

...A series of in-and out-of class experiences with family, peers, faculty members, and staff through which students come to feel accepted in their new community, receive confirming signals that they can be successful in college and are worthy of a place there, have their previous work and life experiences recognized as legitimate
forms of knowledge and learning, have their contributions in class recognized as valuable (p. 15).

This encouragement was critical to the students' persistence in pursuing a degree.

Walleri and Peglow (1988) used a case study analysis of twenty personal interviews with high risk students to highlight inconsistencies in Tinto's (1987, 1993) well established model of factors associated with student attrition. The participants were students identified as academically under prepared through their enrolment in a compulsory academic preparatory program prior to their entry into higher level courses. Tinto's model is based on the assumption that all students come to college to get a degree and that academic and social integration are important predictors of student persistence. Walleri and Peglow (1988) found that these predictors were not important for some non-traditional students, who did not have "definite goals and shared values with the institution" (p. 13). The authors regard incongruencies between their findings and Tinto's model as due to the "the heterogeneous nature of the non-traditional student populations, combined with the limited methodological approaches (i.e. undifferentiated student tracking and standardized surveys)" (p. 1) used in studying this phenomena.

Empire State College (1984) conducted case studies of six mature students who had pursued their post-secondary education through individualized degree programs. The students represented diverse backgrounds, for example, married students, academically at risk students, high academic achievers, students with prior blue collar and professional work experience. They were selected to illustrate how their different educational, vocational and personal goals could be successfully achieved through individualized degree programs. The richness of data in each case study provided a key to understanding "the harmony between individual goals and the educational objectives of the
The relationships between the students' individualized program and the quality of their experience could not have been appreciated without providing the participants with an opportunity to tell their stories.

In summary, the non-traditional students' integration into campus life seems to depend on the availability of social and emotional support from family, faculty, peers and academic advisors. Personalized attention is critical, regardless of whether the support is experienced through a one-on-one relationship with an academic advisor, feedback from a faculty member, a sense of belonging to an identified group, or encouragement from family.

**Researching Disability**

To date, very few qualitative studies have been conducted with students with disabilities, and particularly students with mental illness. The existing research often tends to be focused on needs assessments and services required and is usually presented through the eyes of service providers (e.g., Brinckerhoff, Shaw, & McGuire, 1992; Lang & Connor, 1988; Lundeberg & Svien, 1988; Petronio, 1988; Satcher, 1992). The main conclusions from these various studies emphasize the importance of specialized support services for students with disabilities once they gain entry into institutions of higher learning. These supports include academic accommodations such as extension of time in which to complete examinations, individual counselling and peer support to assist in their social and emotional adjustment to campus life, increased faculty awareness of the needs of various disability groups and linkages with community resources.

Burbach and Babbitt (1988) addressed the first hand experiences of post-secondary students with physical disabilities and their goals for the future. Using questionnaires and structured telephone interviews with 93 students, the authors concentrated their investigation on the students’
experiences of four aspects of the college environment: the physical environment, the academic program, extra-curricular activities and the social environment. In response to the critical question of how they valued their education, the students indicated overwhelmingly that their post-secondary education was “of utmost importance” (p. 13). This response, however, was not elaborated upon in any great depth. Goals for their future were listed in percentages and comprised envisioning themselves graduating, getting a job and marrying (52%), achieving “complete independence” (14%), beginning a career (7.5%) and attending graduate school (5.4%).

Burbach and Babbitt (1988) reported that, although in many broad respects students with physical disabilities differed little from any other group of students (e.g., behaviour, involvement in campus activities), there was a "vast discrepancy between academic outcome and perceived ability" (p.14). While a little more than 20% of the respondents placed their academic accomplishments in the very successful category, 72% of the respondents evaluated themselves as very capable academically. Given this wide disparity between their academic performance and their perceived ability, the authors suggest that this particular population of students was unsuccessful at realizing their self-reported potential. Since these students believed in the efforts of their work, the authors speculate that "their disability becomes a defining element in their formation of self-concept" (p. 19) and suggest that the disability may shape other dimensions of the students' self-perceptions. More open-ended interviews than those used in this study might have been useful in explaining the discrepancy between the students’ actual achievement and their reports of their own evaluations of their potential.

Research on Post-secondary Students with Psychiatric Disabilities

There is a paucity of research studies on university students with mental illness. What little
research exists is quantitative in nature. In lieu of systematic research, there are a few reports on the current state of service provision. However, little data is available on the nature of the services provided or about the number of students who have access to services. The existing reports are presented as a set of simplistic instructions for service providers to follow so that students with mental illness can integrate into campus life.

Unger (1991) surveyed existing post-secondary educational programs for students with psychiatric disabilities. She found that a range of accommodations were available including assistance with registration, financial aid, course selection and course load, orientation to campus, modifications to seating, assistance in note taking, tape recording, extended time for examinations, separate rooms in which to write examinations, workshops for study skills, time management, removal of academic failures when appropriate, a special place to meet on campus and peer support. Wolf and Di Pietro (1992) identified similar and additional components used to integrate students with mental illness into mainstream university life. The additional supports included assisting students to become comfortable in the school environment, providing them with tutorial support and assisting them in handling conflicts with instructors.

In Cooper's (1993) study on supports needed for students with psychiatric disabilities, student services staff, service providers, consumers and their families were asked for their opinions. The respondents identified the following services as the most essential: academic mentoring, greater counselling and out-reach services, peer support, stress and time management training.

Through the use of questionnaires, interviews with consumers, educators and service providers, Loewen (1993) gathered information on access to education for students with
psychiatric disabilities in British Columbia. She identified the need to improve organizational services, increase awareness of mental illness and of abuse issues.

Weiner and Wiener (1996) conducted the first systematic study of the concerns and needs of university students with psychiatric disabilities, interviewing 13 men and 11 women, at a large urban campus. The measures included a questionnaire developed by the first author, and personal interviews based on the subjects’ responses to the questionnaire. The results indicated that the students had problems with many of the academic and social tasks demanded of university students including producing assignments on time, giving oral presentations, studying effectively and writing examinations. Socially and emotionally, they had difficulty disclosing their problems and asserting their needs in a variety of situations. They were quite concerned about career directions and finding employment and were socially isolated. Low self-esteem, heightened anxiety, high levels of stress and depression were identified by more than three quarters of the students as significant issues interfering with their functioning at university.

There was strong consensus about the types of accommodation that had been or might be helpful. Those supports directed to providing social and emotional assistance were seen as especially critical including personal relationships with counsellors and/or academic advisors, peer support groups and career counselling.

In another study, Weiner and Wiener (in press) investigated the decision making process of university students with psychiatric disabilities who withdrew temporarily, with a view to exploring whether the institution could have done anything differently to prevent premature withdrawal. In-depth interviews with eight students revealed that, in spite of the provision of appropriate educational accommodations, when these particular students’ mental health deteriorated, their
academic concerns became a secondary issue. When the illness reached an acute stage, the students had great difficulty attending classes, concentrating on their school work and functioning successfully in the student role. Once they began to miss classes, they were at high risk for withdrawal from their courses.

Both studies illustrate the need for a deeper understanding of the challenges students with psychiatric disabilities face while at university. Though the provision of comprehensive services seems necessary if they are to have full access to postsecondary education, no one has asked students with psychiatric disabilities the meaning for them of their university education and what they would like to derive from the experience.

Some theorists argue for the importance of starting research studies from the lives of marginalized people (Harding, 1993). They claim that all knowledge is socially situated and that "some social locations are better than others as starting points for knowledge" (Harding, 1993, p. 56). By commencing my research from the standpoint of the perspective of students with mental illness (a population of students who are in the minority) and the personal meaning to them of an education, the university (faculty, staff, and administrators) can perhaps learn, not only more about how best to work with these particular students, but how best to integrate all students into the university community.
CHAPTER 3

METHOD

Many researchers (Abberly, 1987; Bogdan & Biklen, 1993; Hahn, 1983, 1993; Fine & Ash, 1993; Jodelet, 1991; Morris, 1992; Oliver, 1992; Stone, 1984; Wendell, 1989; Zarb, 1992) view disability as socially constructed and challenge the traditional research methods and the discourse on disability. Their major concern is related to the failure of traditional research to explore the lived experience of disabled people. Another problem that has been identified with research on people with disabilities is that it is conducted by nondisabled researchers, the result being that the findings are removed from the everyday reality of disabled people (Morris, 1993; Oliver, 1990; Woodill & Willi, 1992). According to Oliver (1990), this tendency objectifies people with disabilities, silences them and alienates their experiences from the research. Although I do not have a psychiatric disability, working so closely with these students, as will be seen later, I did have their trust. In order to obtain rich experiential data, I chose a qualitative approach. I then decided to use grounded theory, an inductive and observable method of gathering and analyzing the participants' verbal reports (Glaser, 1992, 1993; Glaser & Strauss, 1967; Strauss, 1987).

Grounded Theory

Grounded theory is a qualitative research method that entails the development of a 'theory' or model that is 'grounded' in the phenomena being investigated. This means that a goal of the grounded theory approach is to stick as closely to the data as possible in order to produce a general model of a particular phenomenon. Glaser and Strauss (1967), the developers of this approach, recommend grounded theory as a way of generating a theoretical model in an area of study where there is little prior research. By enabling a researcher to tap into the underlying thoughts and
feelings of research participants, grounded theory makes it possible to describe their experiences, based on first hand information.

The purpose of grounded theory is not to verify hypotheses (seek the truth), but rather to discover and to generate hypotheses or explanations to observable phenomena (seek meaning and understanding) based on the subjective experiences of relevant samples of people. This approach has allowed me (as researcher and service provider) to become closely involved with the data collection and analysis and to generate new ways of thinking about university students with mental illness. The specific procedures have also provided me with a highly organized structure and rigorous framework for interpreting the copious amounts of information that I gathered (400 pages of transcripts) in the course of a series of interviews (20) with eight university students with mental illnesses.

I tried to begin my research without any specific hypotheses, a suggestion made by Glaser and Strauss (1967) and by Lincoln & Guba (1983). Although I had a general sense that the illness would play a role in the experiences of my participants, as it had in previous research conducted on students with mental illness (Weiner, 1996; Weiner & Wiener, 1996; in press), I had no clear idea as to how the illness would influence the students in the current study.

Grounded theorists tend to avoid conducting an exhaustive literature review at the outset of their research until concepts become well established, thereby allowing ideas to emerge from the data. Once main themes emerge, a more extensive literature search in related fields can be conducted. In the present study, during the more advanced stages of the analysis, relevant qualitative research studies of the trajectory of chronic illnesses in the nursing literature were utilized. This
material helped enormously to enrich my data analysis and will be explicated more fully in the discussion section of my paper.

Sample

Selection of Participants

According to Glaser and Strauss (1967), data collection should begin by selecting participants who are relatively similar so as to be inclusive of the phenomena being investigated, but also allowing some diversity to insure representativeness. My sample consisted of eight university students, all of whom were living with a mental illness and studying at the same university. The participants differed in age, gender, cultural background, onset of illness, symptomatology and year of study.

Eight students with a diagnosis of a mental illness by a psychiatrist in the community participated in the study. I chose students with whom I had prior acquaintance through an ‘on-site’ supported education program that I co-ordinate at a large urban campus, and with whom I had a rapport. Appendix ‘B’ provides a description of the service. Each student had participated in at least one of the services that the counselling department on campus offers students with mental illness. These services include: a weekly peer support group, academic coaching, individual counselling, psychiatric consultation as needed and advocacy.

Anticipating that the interviews would be lengthy and involve audio-taping of the sessions, I had to insure that I would be interviewing students whose conditions would not be aggravated by the process of data collection. I had to take into consideration whether I felt that they were well enough to be able to handle an intensive series of interviews. Prior knowledge about the participants helped in the selection process. I also deliberately selected students who were known to me because
I felt that self-disclosure would be less problematic, given we were acquainted and I had their trust. Our acquaintance enabled me to enter the field in a relatively unobtrusive manner. In a prior study of university students with mental illness (Weiner & Wiener, 1996), the students said repeatedly that they would not have participated in the study had they not known me personally and trusted me. As Crowson (1987) observed, the more that researchers are regarded as credible by the participants in a study, the less time they will need to spend gaining trust and co-operation.

All of the students but one were on medication, and all had chronic psychiatric conditions, with different levels of involvement with the mental health system. Two of the participants had never been hospitalized for their illness, while the remaining six had. Two of the participants were women, six were men. Six students were Canadian. One student was from the United States and a second one was from South America, although both had been in Canada for over twenty years. None of the students belonged to any visible minority. Their ages ranged from 21-46. Table 1 summarizes the major characteristics of the participants.

**Procedures**

**Consent**

The sensitivity of the material that I proposed to discuss with the students in this study required that I explain to them in detail the ethical constraints within which I would be working. I had to insure confidentiality so that the information would not be recognizable.

I first approached (either in person or by telephone) nine students with whom I had been working, and asked them whether they would be willing to participate in a study of what their education means to them. They were told that it was part of my doctoral thesis and that the
TABLE 1

DEMOGRAPHIC INFORMATION

<table>
<thead>
<tr>
<th>NAME</th>
<th>GENDER</th>
<th>AGE</th>
<th>DIAGNOSIS</th>
<th>MARITAL STATUS</th>
<th>COUNTRY OF BIRTH</th>
<th>DOMICILE</th>
<th>YEAR OF STUDY</th>
<th>YEAR OF ENTRY</th>
<th>HOSPITALIZATION</th>
<th>MEDICATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bob</td>
<td>Male</td>
<td>21</td>
<td>Manic Depression</td>
<td>Single</td>
<td>Canada</td>
<td>Family</td>
<td>Second</td>
<td>1993</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Anne</td>
<td>Female</td>
<td>23</td>
<td>Depression</td>
<td>Single</td>
<td>Canada</td>
<td>Independent</td>
<td>Fourth</td>
<td>1991</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Doug</td>
<td>Male</td>
<td>23</td>
<td>OCD*(a)</td>
<td>Single</td>
<td>Canada</td>
<td>Family</td>
<td>Third</td>
<td>1990</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Mark</td>
<td>Male</td>
<td>24</td>
<td>Schizophrenia</td>
<td>Single</td>
<td>Canada</td>
<td>Family</td>
<td>Second</td>
<td>1990</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Mary</td>
<td>Female</td>
<td>38</td>
<td>Schizo-Affective Disorder</td>
<td>Married</td>
<td>Canada</td>
<td>Spouse</td>
<td>Second</td>
<td>1988</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Omer</td>
<td>Male</td>
<td>40</td>
<td>OCD/Anxiety</td>
<td>Single</td>
<td>South America</td>
<td>Family</td>
<td>First</td>
<td>1978</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Jeff</td>
<td>Male</td>
<td>44</td>
<td>Schizophrenia</td>
<td>Married</td>
<td>Canada</td>
<td>Spouse</td>
<td>Third</td>
<td>1969</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Sid</td>
<td>Male</td>
<td>46</td>
<td>Depression</td>
<td>Divorced</td>
<td>United States</td>
<td>Friends</td>
<td>Second</td>
<td>1969*(b)</td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>

*(a) OCD -- Obsessive-Compulsive Disorder

*(b) Sid began his university studies in the United States where he was born. The year of entry for all other participants began at the educational institution where this study took place.
interviews would be audio-taped and then transcribed. One student declined to participate, while the others foresaw no major difficulties. For those who agreed to participate, I then gave them a formal letter telling them about the study (see Appendix ‘C’). The letter reiterated what I had told each person verbally; it stressed both confidentially and voluntary participation in the study. Students were told that they were free to withdraw at any time. Given the dual nature of my position as a doctoral student at O.I.S.E. and as coordinator of an advocacy service on campus, it was important to stress that refusal to participate in the study would have no effect on the services that they would continue to receive from my department. As stated, eight students agreed to be part of the study.

Interviews

Setting and Timing of Interviews

All of the participants were attending a university situated at the edge of a large metropolitan area in Ontario. The student population, which is approximately 42,000, consists of both residential and commuter students. All of the students in this study were commuter students. The university administration is committed to providing supports and services for all of its students. A separate college within the educational community has been established to meet the unique needs of mature students, many of whom are working and can only study part-time. Courses are offered to them in the evenings. In the mid 1970s a support service was established for students with physical disabilities. Once part of the counselling services, this department is now a separate division. Within the past five years, students with physical disabilities have been able to live in residence because of 24 hour attendant care provided by the March of Dimes. In 1985 a support program for students with learning disabilities was established. In 1990 an additional service for students with
psychiatric disabilities was developed. Both of these programs operate through the university counselling department.

In the early 1990s the university adopted a Senate policy that requires faculty to provide academic accommodations for students with disabilities. Accommodations such as separate rooms and extra time in which to write examinations are established on the recommendation of personnel attached to the three special needs programs mentioned previously. Some of the procedures in place at the university that are meant to facilitate the integration process for students with disabilities can also cause difficulties for them; for example, while a process is in place for students to formally petition deferred standing for courses in which assignments and examinations have not been completed, the procedure is lengthy and involves a written letter from the students explaining their circumstances, as well as documentation from a doctor or counsellor. Under the current structure, every request that is made by the student is viewed by the administration as a 'special' request. The same procedures have to be followed, no matter how many times a student petitions. Although members of the petitions committee will take into account extenuating circumstances, having to write one’s personal story to strangers and wait for a response that is sometimes delayed because of overload can produce anxiety in these students.

In order to minimize the degree of stress which the students would be experiencing, I began the interviews in the spring and summer after the students had completed most of the previous term’s assignments and examinations and were generally feeling more relaxed and under less academic pressure. The interviews were held between April and September. All of the students were seen during a period of remission and on a day when they felt asymptomatic. Some interviews had to be
re-scheduled, for example, because they were feeling particularly depressed or anxious. The students themselves were assumed to be the best judges of when they felt they could come in for an interview.

I interviewed all eight students individually in my office. The initial interviews took anywhere from one to two hours, depending upon how the students felt and how verbal and reflective they were about the questions that I asked. General life circumstances resulted in one student experiencing a setback after the initial interview. This student was not able to be seen for the second interview until five months later. The students’ individual backgrounds will be described more fully in chapter four.

Content of Interviews

Using semi-structured interviews, I addressed the following questions:

1. What did they see as the meaning of their education?

2. What were their goals for their education?

3. Had the meaning of their education changed? If so, at what point, in what ways and why?

4. What barriers and supports had they experienced at university?

5. What were their opinions about university policies and procedures for students with mental illnesses?

6. What advice would they offer a student in a situation similar to theirs?

Interviewing Process

Each interview was taped, transcribed, coded and analysed before proceeding to the next interview. All eight students were interviewed a second time to clarify the data, expand on certain
emerging themes and receive feedback on the transcripts. Three of the eight students were interviewed a third time, and one a fourth time, for further analysis of the data.

In an effort to be sensitive not only to the spoken words but also their moods, I had to pace the interviews according to how the participants were feeling and behaving (e.g., depressed, hypomanic, restless, lethargic). It was important to sense their fatigue level, their need for frequent breaks and for liquids because of the side effects of medication. In order to minimize the participants' anxiety and any misunderstandings, I initially chose to present them with transcripts in my office where they were given the opportunity to read them. I noted how, for some, their short attention span and difficulty maintaining focus made reading their transcripts difficult. I soon became aware that having them read the transcripts and then be interviewed was too draining. Subsequently, each participant was given the transcript well in advance so that he or she would only have one task to do at the time of the second interview. These earlier observations in the field helped me appreciate just how difficult it must be for some of these students to be able to sit in two to three hour lectures and to read copious amounts of material for their course work.

Data Analysis

One of the key assumptions of grounded theory is that data collection and analysis are intimately linked (Glaser, 1992). A continual comparison of new data with emerging findings leads to the construction and refinement of a tentative model that remains open to further investigation and analysis.

The research investigation involved several stages: data collection, coding (Glaser & Strauss, 1967) or open categorization (Rennie, Phillips, & Quartaro, 1988), the writing of memos, re-coding, the identification of the core category, sorting of memos and the development of a grounded theory
or model. These steps will now be described both in general terms, and in terms of how they were carried out in my particular study.

Data Collection/Coding

Data collection in qualitative research is "the finding and gathering - or generating of materials that the researcher will then analyse" (Strauss, 1987, p. 20). After each audio-taped interview that I conducted, I transcribed the tapes, numbering each line of the transcript consecutively. I then coded the transcript, segmenting it into meaning units or individual thoughts or themes that were conveyed by the participant (Rennie et al, 1988). These thoughts included, for example, feelings, wishes, suggestions and concerns. Although Glaser (1978) recommends a line by line analysis of the data, I followed the variation prescribed by Rennie et al (1988) and divided the transcript into meaning units that varied in length depending upon the individual ideas and their characteristics. These meaning units were assigned to categories that reflected their particular context. Rennie et al (1988) refer to this stage of analysis as "open categorization" (p. 143) and Strauss and Corbin (1990) as "open coding" (p. 14). These categories were then transferred onto index cards with a notation of their page number and line numbers. In keeping with Glaser and Strauss's (1967) recommendation, I tried to ensure, at this early stage of analysis, that the categories were descriptive and closely reflected the language that the students had used. In this "open categorization" process, a given meaning unit can be assigned to more than one category. This process provides the basis for the development of a rich theory. For example, when talking about his obsessive compulsive disorder, one participant said:

When I was in class I would cover my notes because I wouldn't want anyone to see what I was doing because it was very embarrassing to have to write things over and
over again. Just generally my handwriting is really crappy. It's embarrassing. Sometimes I look at it and I think I shouldn't be here. I should be in kindergarten because it looks childish and the quality of my notes looks really bad. This also tends to build a barrier between you and your professor because you are a lot less likely to ask questions to people after class if you are concerned about things.

This meaning unit was initially coded into the following descriptive categories and their specific characteristics or properties: "the impact of D's illness on his writing" (has to "write things over and over again"), "the impact of D's illness on self-esteem" ("I wouldn't want anyone to see what I was doing because it was very embarrassing...Just generally my handwriting is really crappy."). "impact of D's illness on asking for help from professors" (This also tends to build a barrier between you and your professor.) and "the impact of D's illness on asking for help from peers" ("You are less likely to ask questions to people after class."). The purpose of this descriptive process is to have the researcher adhere closely to the data and allows the complexity of the process to emerge.

In the later stages of analysis, the researcher is more at liberty to construct his or her own language for the naming of categories. Lower level "descriptive"categories were subsumed into higher level ones such as "impact of illness on academic functioning," "impact of illness on emotional functioning," "impact of illness on social functioning" and "impact of illness on behaviour." These "constructed" categories were then eventually subsumed into the still higher level category of "impact of illness on university experience."

**The Writing of Memos.**

Just as coding is begun early on and throughout the analysis, so is memo writing. "Memos
are the theorizing write-up of ideas about codes and their relationships as they strike the analyst while coding" (Glaser, 1978, p. 83). The purpose of writing memos is to prevent the researcher from losing his or her insights or ideas, while keeping them from an influence on the categorization process. Memo writing is also meant to assist in the generation of categories that are "constructed" versus "descriptive," and to assist in the emergence of a core category and the development of a theory or model.

By recording one's thoughts and biases, one openly acknowledges that the inquiry is value laden (Crowson. 1987. Bogdan & Biklen. 1982. 1992; Lincoln & Guba. 1983). According to Tesch (1990), memos "record the reflective and the concrete process, and therefore provide accountability" (p. 95). It becomes easier to read the research critically if these assumptions are incorporated honestly into the data. For example, one of my memos written on September 22 was as follows:

While the aim of my research is to come to know the social world of the participants, I am learning just as much about myself in the process. I have once again been confronted by my biases in doing the study. The concept of figure/ground is a perfect example. I think that for Mary her illness is figure and university is ground, and yet for her, university is figure and illness is ground. I have to continually remind myself that I am doing this study to gain access to the students' perceptions, while mine keep getting in the way!

Memo writing helped me conceptualize the data. It was an exciting part of my analysis, as it encouraged me to think more abstractly and therefore more creatively about my findings.

Re-coding

As new information was accumulated from each interview, I determined that previous
interviews had to be re-coded. It was necessary to conduct additional interviews until a category became saturated. Saturation of a category occurs when, in coding and analysing the data, no new 'properties' (i.e., identifiers or new information about the categories and sub-categories) emerge. See Table 2 as an example of the saturation of the category, "purpose of education."

Once categories became saturated, I was able to make further connections between higher level categories, their sub-categories and their properties. For example, in the experience of one participant, the category of "self-acceptance of the illness" was seen as accepting one's limitations. whereas, for a second participant, self-acceptance was characterized by a sense of giving up. Feelings of self-acceptance and self-confidence predominated within the context of a peer support group, while feelings of shame and doubt predominated within the context of a classroom situation. The category of "academic accommodations" was seen as an educational support by all students, and also as a charity for some.

Using the constant comparative method, linkages are also made between different categories. For example, I saw similarities between the category of "managing the illness" and the category of "accepting the illness." I noted differences between educational supports (an understanding professor) and barriers (an unsympathetic professor), and how these differences affected the students' self-esteem. Properties of the category "stigmatization" (feelings of doubt, fear, shame, difficulties with self-disclosure) became linked to properties of the category "accessing support" (feelings of intimidation, shame, privilege, fear of self-disclosure), and to the categories of "acceptance and understanding of mental illness by-self and others" and "managing the illness." In this way, the constant comparison method of analysis provides the ground work for the development of a dense theory (Glaser & Strauss. 1967).
Table 2

Properties

<table>
<thead>
<tr>
<th>Purpose of Education</th>
<th>Provides structure</th>
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<tr>
<td></td>
<td>Provides routine</td>
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<td></td>
<td>Provides discipline and focus</td>
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<tr>
<td></td>
<td>Provides hope/reason to live, motivation</td>
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<td></td>
<td>Provides a distraction/somewhere to go and keep busy</td>
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<td></td>
<td>Provides a future/career, better job, financial gains</td>
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<td></td>
<td>Provides intellectual stimulation and knowledge</td>
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<td>Provides enjoyment</td>
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<td>Provides social contact</td>
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<td></td>
<td>Provides empowerment</td>
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<tr>
<td></td>
<td>Proves to others they are capable - family expectations</td>
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<td></td>
<td>Shapes their identity</td>
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<td></td>
<td>Normalizes their lives</td>
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<tr>
<td></td>
<td>Develops self-confidence</td>
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<tr>
<td></td>
<td>Removes some from psychiatric rut</td>
</tr>
<tr>
<td></td>
<td>Assists in the recovery process</td>
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</table>
Identification of the Core Category

Through a process of abstract thinking, that is, generating concepts from the data, what Glaser (1978) refers to as “theoretical sensitivity,” the researcher subsumes lower level descriptive categories into higher level categories and eventually into the identification of a core category. The core category is the one that is “most densely related to the other categories and their properties” (Rennie et al. 1988, p. 144), and is usually an abstract concept. This means that, in linking together all the other categories, the core category becomes central to the integration of the data. (See chapter five for a description of the emergence of the two main categories and the core category.)

Although categories may reach saturation and a core category may be constructed from the data, there is not meant to be final closure to qualitative research. The results are not indelibly printed on the pages as the final text but “should be readily modifiable” (Glaser. 1993, p. 15) when new data are presented. Lather (1993) refers to these representations as ‘partial texts and partial voices’ versus the ultimate truth. The findings are meant to provide an understanding that is always open to further analysis.

Sorting of Memos/Final Model

During the advanced stage of analysis, memos were written in response to initial memos. For example, a few months later I made the following comments on the initial memo recorded on page 33.

As I have been writing up the students’ personal histories, I have come to better understand how the shift in meaning of their university education depends upon how the illness presents itself at a given point in time. I had locked myself into a static figure/ground concept, while it shifts and changes weekly, daily, even hourly!
It was through the written recording of my thoughts that I was better able to make linkages among the various categories and eventually establish a core category. This process contributed to the refinement of the core category, that in turn created my model.

**Determination of Validity**

Internal validity of a qualitative research study is best achieved through two methods: (a) consensual validation including use of participant debriefing, and (b) confirmability of someone else's audit including peer debriefing (Lincoln & Guba, 1983; Whitt, 1991). These concepts are explained below.

**Consensual Validation**

First, I verified the status of the participants' psychiatric diagnosis from psychiatric documentation on file in the counselling centre. Second, all the participants were interviewed at least one other time after they had an opportunity to read their initial transcripts, in order to enable them to make clarifications, address contradictions and modify or make any additions or deletions to the data. Three of the eight participants were interviewed a third time and one a fourth time in order to gain further insight into the data. As I see most of these students on a regular basis, I kept the participants informed about the findings as they emerged during the analysis. One of the participants read chapter five, 'Results and Discussion' and said that the analysis of the data "rang true" for her.

I am keenly aware that, as the author of this thesis, I am in a difficult position of representing another's subjective experience. I am also aware that, as Boydell et al (1993) observe about persons with mental illness, many of these students will have experienced some sort of social control by the mental health system. I certainly did not want to write about the participants in any way that would
be harmful to them. The most important point is that the stories remain their stories. I had all the participants read their own personal histories in order to ensure that my representation of their personal stories was indeed an accurate reflection of their own thoughts and not my personal reactions.

**Confirmability of Audit**

With the permission of most of the participants, I had a trusted friend and colleague read through their transcripts to insure that I had a good grasp of the data. This audit helped move my thinking to a deeper conceptual level.

I talked with my thesis supervisor on a regular basis, with members of my thesis committee and several colleagues in the field of psychology and education to help validate my ideas. While not disclosing the names of the participants, this process helped crystallize my thinking. For example, as the metaphor of figure/ground (previously described in my memos) emerged around the shifts in meaning of the students' education, one colleague insightfully challenged my thinking by asking me to whose figure and whose ground I was referring, the students or my own. This was very useful feedback as it helped me to confront my biases about the illnesses and the students' reasons for being at university and extended my thinking about the interactive relationship between researcher and participants.

**Interviewer/Interviewee Relations**

My dual role of researcher and service provider may have led to the presence of investigation bias. The participants, however, were fully aware of my role as student/researcher and service provider. I was also asking them questions that did not have them personally evaluate my role as their advocate on campus. Generally, I found that the students' strong interest to participate in the
study was motivated by their sincere desire to educate members of the university community about their experiences and to have an opportunity to contribute to the experiences of other students living with a mental illness.

Stanley and Wise (1993) refer to the unspoken power relations between the interviewer and interviewee in all research. Although inherent hierarchies exist within the research process, they did not appear to prevent the students from giving me honest feedback about transcripts at the second interviews. Because I knew the students, I felt that they probably disclosed more in the interview than they might have done to a stranger and that my acquaintance was more often an advantage than a bias. For example, one participant said that the first interview did not flush out for him what the real issues were. Another student told me quite honestly that she was looking forward to the completion of my thesis, as she did not feel I was available enough to her.

The difficulty I encountered dealing with my dual relationship as researcher and service provider lay less in conducting the interviews than in the writing-up of my findings. I had problems setting boundaries around when the research, for the purposes of this particular study, ended. I attributed my difficulty in setting limits, in part, not only to the fact that I saw these students on a regular basis, but also to the trajectories of the illness experience and the university experience. Since I work so closely with these students, I am witness to the fluctuations in their daily lives and to the frequency with which their moods can change in response to both internal and external stresses. I was conscious of the interviews being a fixed point in time in relation to these fluctuations and felt fortunate that I was able to meet with each participant at least a second time, since their lives are fraught with challenges and interruptions.
Throughout the interviews, I saw myself as the student and the participants as the teachers. They were the experts who informed me about their experiences. Although I have conducted qualitative research with university students with mental illness before (Weiner, 1996; Weiner & Wiener, 1996: in press), I learned so much about the participants as individuals and as a unique student subgroup, that I felt I was exploring new ground. I became increasingly aware of the illness itself, of its unpredictable and sometimes devastating course. I learned more about the subjective aspect of mental illness, these students’ daily lives, how the illness impacts on their everyday experiences and how those experiences are qualitatively different from most of the students who come to the counselling department for therapy. Although their concerns are similar to other students, I now have a greater understanding of the intensity of their experiences; how other students can be more resilient in the face of a setback and be able to “get back on track” in a few days or a week, whereas with these students it might take them months. These ideas will be explored more fully in chapter five.

**Ethics of Interviewing and Non-Intervention**

Any issues that arose pertaining to my role as advocate were put on hold until the end of the interview. For example, Bob described a situation where he had difficulty getting into a summer course. This information was important for me to know as a service provider and was dealt with once the interview had ended.

It was not uncommon for me to hear the participants speak about themselves in very negative terms. Self-deprecating remarks included statements like: “I don’t feel like I am a worthwhile person to know.”... “Sometimes I think I talk a mish mash of nonsense.”... “I feel like I am the accountant of a fishing company and the best thing to do would be to close shop.” Hearing these
comments made me want to intervene and validate the students, not only in the interviews, but on paper as well. For example, in writing up the personal histories, I found myself wanting to talk about the sensitivity that I observed in how they related to the other students in the peer support group, to myself following the death of my father, or about their courageous participation in a wilderness experience that I had organized the previous year. I had to stop myself from including this extraneous information that spoke to their additional strengths and adhere strictly to the data from the interviews. These reflections resulted in my producing a category called “against all odds.” to which I shall refer in chapter 5. It is important to note that though no students were actively suicidal, if such were the case. I would have had to remove my hat as researcher immediately and intervene as therapist.

The Researcher as Human Instrument

The data of this study were drawn from the students’ verbal responses to the interview questions. However, it was difficult at times, even for the participants, to express the complete nature of their experiences. Some found it easier to articulate their innermost thoughts and feelings than others. There was great disparity in terms of the participants’ abstract and reflective thinking abilities. In order to deal with these disparities, I found myself drawing on the resources described by Guba and Lincoln (1981) in their discussion of the qualitative researcher as “human instrument.” Guba and Lincoln (1981) speak about the multi-level demands placed upon the qualitative researcher (e.g., use of self, understanding of his/her experience and the participant’s experience, sensitivity to the interactive relationship with the participant, attention to nonverbal cues such as body language, mood, tone, pacing, understanding of social/cultural contexts, ability to amplify, clarify, interpret and report contextually).
The participants’ heightened sensitivity sometimes resulted in misperceptions of my questions. For example, when I asked one participant to elaborate more on the purpose of her education, the response was: “It provides an intellectual outlet...It’s rewarding...I wouldn’t come if it wasn’t.” The latter statement was spoken with subtle anger and defensiveness. I realized early on how easily my questions could be misinterpreted. Stiles (1993) refers to this art and science of the qualitative investigation as “the polydimensionality of experience” (p. 596).

I asked the participants whether they thought that I, as a service provider, had focused too much on their illness. The response was an overwhelming ‘no’. They all saw their illness as a major component of their education.

**Presentation of Personal Histories**

In the next chapter of my paper, I describe each of the participants’ stories in the format of personal histories, so as to provide the reader with greater insight into who these individuals are and what their university education, at this particular campus, at this particular point in time in their lives, meant to them. Hopefully, in this way, the reader will not only come to know these students more intimately, but also come to acquire a greater knowledge about psychiatric illnesses and to realize that mental illness is understandable. In chapter five, ‘Results and Analysis’. I describe in greater detail the results of my grounded theory analysis. This chapter includes a discussion of the two main categories and core category, and a conceptual model that incorporates the core findings. The implications of my findings are discussed in chapter six, the final chapter of my thesis.
Chapter 4
PERSONAL HISTORIES

A personal account of each of the eight participants is presented chronologically, in order of the participants’ ages, from youngest to oldest. Pseudo names were used so that the information would not be recognizable. These vignettes are based on information in the transcripts and include: personal and family background, history of the students’ illnesses and educational paths. The nature of the illness is described in terms of the students’ subjective interpretations of their disabilities. The illnesses are also described in light of how they affect the learning process (academically, socially, emotionally and behaviourally) and how they are managed by the students. The university experience is presented both in terms of the barriers and supports that influence the students’ learning. Based on this information, each personal account culminates in the personal meaning that university education holds for the participants.

Bob

If you think of the illness always impacting on you, it’s a negative connotation. If you think of it the other way around, you helping the illness, you as a student are trying to finds ways to adapt to your illness, it’s more positive. It’s like you conquer it rather than it conquers you.

Educational, Personal and Family Background

Bob, age 21, is the youngest of three brothers, two of whom attend the same university. His mother has a university degree: his father took college night courses in bookkeeping and accounting.

Bob entered university as a full-time student in 1993 and experienced his first manic episode during the second month of his freshman year. Although he hoped to remain in school, his first
hospitalization was longer than he had anticipated and he withdrew from his courses. He attempted to return to university for the winter session. Unable to concentrate, he quickly realized that he was not ready to engage in his studies. Following his unsuccessful attempt to return to university, he enrolled in a four month non-credit community college program designed to help in the rehabilitation of individuals who are recovering from a mental illness. Since his return to university in 1994, he has taken a reduced course load.

Bob describes his family as being extremely supportive. Their understanding, he believes, helps him to cope better. If he needs to "let off steam" and runs into difficulties because of his illness, he will talk to his father and older brother. His parents, like his therapists, warn him to be cautious and not to take on too much work. He says that he would much prefer to hear this advice from professionals than from his parents. Acknowledging that his mother and father have the right attitude, he still wants to establish his independence and do things for himself.

Even though he becomes irritable and depressed, Bob says that his friends see him as an outgoing person. Only a couple of his close friends know that he has manic depression. He states that his other friends do not understand why he is taking only two or three courses. Beyond his immediate family, he does not tell many people about his illness.

People are going to stigmatize me. The more people know, the more you are going to experience trouble. It's a big risk. With this illness you see yourself as different. I know that this is the wrong attitude to have, but if I had diabetes, people would not view me differently.

He is equally selective in what he discloses about himself at the various jobs he holds - swimming instructor, lifeguard at summer camps and supply teacher for a local school board. If people knew
about his illness, he believes that they would view him as “different.” and perhaps find a reason to fire him.

**Nature of the Illness**

Bob has a bipolar disorder, otherwise known as a manic depressive or mood disorder illness. He describes the illness as follows:

It is basically a chemical imbalance in the brain. It means your moods are out of whack. Hormones are imbalanced. It’s a fluctuation up and down of stable and unstable periods.

I have to take one day at a time because things change so much. It’s never a steady depression of three or four months. The depressions are always quick, like half a day.”

Bob has what is called “rapid cycling” (frequent and rapid shifts in moods). “I experience mania and depression, sometimes separately, sometimes together.” Generally he experiences the two conditions separately, although, they sometimes occur simultaneously in what is called a “mixed state.”

I have to really watch it at those times because while my mind is racing I have suicidal thoughts. I have to go into the hospital then. That’s when I feel really scared. You think the whole world is against you and nobody cares if you die. Part of depression and mania are paranoid thoughts. When I am manic I don’t sleep enough. When I am depressed I sleep too much, and when I’m in a mixed state I don’t sleep at all.
He thinks that he is more fortunate and better able to function with "rapid cycling," however, than he would if he experienced extended highs or lows.

**The Impact of Bob's Illness on his University Education**

Bob does not find academic work difficult and says that he has no problem understanding it. During periods when his illness is stabilized and his motivation is good, he does not see his illness as affecting his education "that much." When he is depressed and his mood is unstable, he finds it hard to study. At these times, he sees his illness affecting his educational goals because of his difficulties with motivation and lack of concentration. When sitting in lectures or writing tests and examinations, his mind wanders. When he studies, he can only sit for twenty minutes and then he needs to take a break. In combination, these symptoms interfere with his ability to "function effectively" in some of his courses. "When I am in a low mood or depressed, it's very hard because I have no motivation to do the work." He wishes he had a "duracel battery" in his back so that he could keep "going and going."

During a particularly bad day, because of his moods, Bob may choose to stay at home and sleep instead of going to classes. "When I have a down mood, I just have to ride it out." He has to reduce his activity level at those times.

Sometimes, because of the large number of people in a class, Bob starts to feel paranoid. In order to control these symptoms, he takes medication at their onset and finds that it takes effect in about half an hour. In class, he prefers to sit with people he knows, to help increase his comfort level and to "take the edge off" his anxiety. Sometimes he may have to leave the class and "take a break."

Bob remarks that mental illness, in his case manic depression, takes away from one's self-confidence. He finds that since he developed his illness that he has become more sensitive.
I come across as joking or sarcastic, but I'm more conscious of different social situations in terms of people and the way they relate to me and to other people. Whenever I say something, I question what I said. Was it the right thing? I feel insecure and judge myself.

Although he sees himself as being in tune with how people are feeling, he also sees a danger in his over sensitivity. "When you are sensitive it's not always good because your judgement of what you perceive is going on in certain situations is not always correct."

**Supports on Campus**

When he needs assistance, Bob finds it helpful to have a contact person at the university who is able to act on his behalf in a number of ways. These supports have included writing letters to his instructors identifying his academic needs, assisting him with petitions when he has had to withdraw early from a course, and providing academic advice regarding course selection. He has also had one-on-one support from a learning skills specialist. He views the support service on campus for students with mental illness as "a place to go if you get into trouble as far as education goes when the illness interferes with your studies." It is also a place for him to discuss other personal problems that may arise. In addition, Bob finds his involvement with student groups on campus to be beneficial. At the weekly meetings of the campus support group for students with mental illness, he learns of other people's experiences, such as how they manage courses and deal with professors. He has been active in one of the social clubs on campus and volunteered to be on their executive body. His courses are also attended by former high school friends, on whom he can call for notes if he misses classes, due to illness.
Bob makes a clear distinction between the help he receives from his psychiatrists and the staff at the hospital where he receives treatment, and supports he receives on campus. Although he acknowledges his doctors' expertise in the area of his illness, his medications and the effects of stress on his moods, he says that “there is only so much they can do in regards to my university experience.” He does not regard them as being “in tune with what’s happening with professors and with papers.” nor as having “the same power at the university as someone working strictly in that environment.” He views his therapists as helping him to manage his illness, and the educational supports on campus as helping him to manage his learning.

In general, Bob has found most of his professors to be understanding about his situation. He sees them as playing a significant role in his educational experience.

No matter how much you or a group here can help, you are always going to meet some professors who are ignorant about mental illness. Most professors will be understanding, but there will always be some who won’t be.

One of Bob’s symptoms is impatience. This trait makes standing in line and trying to get into overcrowded courses very difficult. It also adds to his problems in dealing with “administrative hassles.” He thinks that there should be priority enrolment for students with mental illness, especially after they have experienced a relapse.

Managing the Illness

Bob sees it as important to control his illness. For him, control means that “when it comes to a period of lowness or unstableness. I'll know what to do and how to react and how to treat it myself and with professionals.” He tries to manage his illness like a physical illness: “You have it.
you take meds for it, you are getting better.” He sees his illness as “going hand in hand with university life and having a big effect on it.”

Bob uses a day planner to organize both his medical appointments and his academic assignments. Though he takes a mood stabilizer as well as a sedative when his mind “starts racing”, he employs several non-medical strategies to treat his illness. When he becomes depressed, he tries to “ride it out, take a nap or go for a walk.” “When I get real high, I have to go into the hospital.” He has learned to recognize early warning signs of his high and low periods. He knows that he becomes giddy, speaks rapidly, and laughs a lot when he is in a high cycle, and that in his low cycles, he becomes irritable and thinks negatively. “I can tell when I am getting irritable.” He engages in positive self-talk to help him slow down when he is under pressure and tries to do too much. “I have to stop and say this is too much for me.” He also uses self-talk to motivate himself. “If I don’t succeed, if I get a poor mark, I say okay, I tried, but I have to remember that I have this illness and it’s a limitation.”

Bob believes that “the more you know about yourself and the illness, the better you can achieve your educational goals.” He has a good understanding of his illness and accepts his limitations.

Acceptance of the illness means having to realize that you have limitations academically because of the illness, and that you need to take a reduced course load. You have to think about your limitations, what you can and cannot accomplish. You learn to set goals for yourself according to that. Although, he thinks that he has gained some understanding and acceptance of his illness from his doctors and teachers at the hospital, he says:
You have to figure out the rest on your own. You have to realize that if you are taking on too much, for example, your course load or extracurricular activities, that you have to learn to forget about some things.

Bob would tell other students with a mental illness what his parents tell him. “to take it slow, year by year and not to be a superman.”

The Meaning of Bob’s Education

*When I have good moods and when I have good thoughts and feelings, I see myself having a profession and that keeps me going. When I have problems with motivation, concentration and bad moods, I am afraid that my illness will inhibit my goals to complete my courses because I won’t be able to do the work.*

“With a little help from people,” Bob sees university as “a recovery process.” Being around people helps raise his self-confidence and keeps him from being reminded of his illness. He is at university to get a degree that he hopes will lead to a career in either teaching or social services. He also identifies a social purpose for his education, which is to interact with people his own age, who have similar interests. He believes that his reasons for being at university are not any different from those of most students. He tries to keep his educational goal in mind. “but things fluctuate.”

Although he does not lose sight of his long-term goal of earning a degree, he focuses more on the short-term goal of “just trying to get by everyday.”

The intrinsic meaning of his education has not changed for Bob since the onset of his illness. The main difference he sees between himself and other students in terms of his education is that it will take him longer to complete his program because of his reduced course load. “When I get sick and have to go into the hospital, my work load changes. I may have to drop a course here and there.
It just postpones my goal longer.” He also has to study harder and more consistently. On the whole, Bob sees being at university as the central purpose of his life “right now” and is “confident” that he will achieve his goals.

Anne

*Sometimes I think of having an ongoing problem, and then other times I don’t consider it to be a problem. I guess because I have been able to succeed so well.*

*Sometimes I think to myself; what if I didn’t have this problem? What would I be doing? Would I be even more exceptional?*

Educational, Personal and Family Background

Anne, age 23, grew up on social assistance. Her father, a graduate from art college, eked out a precarious living as a painter. Her mother, who now works as a supply teacher, began university when Anne was 14. At 16, Anne left home to live with a boyfriend. Her father was diagnosed with AIDS at around that same time and died three weeks after she began university, in 1991. A younger sister, who dropped out of college, lives on welfare.

When Anne was a child, she did well scholastically. “I won a lot of competitions and I was the best student in the class.” Anne says that she became depressed between 14 and 15 years of age and dropped out of an alternative high school in grade ten. She feels that she was always expected to be perfect and views her academic withdrawal as “a way of showing people that I wasn’t as okay as I appeared to be on the surface.” During her year out of school, she worked part-time and “did a lot of drugs.” That summer she joined a youth theatre program, for which she was required to be “drug-free.” and which, she feels, motivated her to return to high school in the fall. She graduated from high school with a 95 average and entered university on a full scholarship. She said that she
always knew she was going to university. “I was almost primed for it. My mother was expecting me to go. It was thought I would transcend the family and that I would be successful.” Anne also realized early on that she would have to educate herself if she did not want a “boring job.” She relates that she has always enjoyed learning.

When she entered university, Anne registered as a theatre major. In her second year she began a minor in psychology, which re-directed her interests. By her third year she had become less enamoured with theatre and more interested in psychology. Pursuit of this interest resulted in her becoming “less aimless and more focused” on her studies. Anne plans to pursue a doctoral degree. She states that she has the backing of her professors, who have been very encouraging.

Anne sees herself as unique in that she has a number of mental health problems - drug addiction, chronic depression and a dissociative disorder, although the latter has never been officially diagnosed. She says that she stopped taking drugs when she was in first year university. She still drinks, though less heavily than before. On the whole, Anne does not see herself as sharing the same experiences as most students on campus. Although she knows that she is generalizing, she views most students as coming from “nice suburban families where both parents are together and pay for their children’s education;” she states that her experiences are “not like that.”

During Anne’s first two years of university she experienced several episodes of depression. Her marks dropped to ‘B’ and ‘B+’. At the time, she was very involved in extra-curricular activities, such as co-editor of a theatre journal, peer advisor and contributor to the student newspaper. In her third year, Anne’s depression became so severe that she was hospitalized for several weeks. “I hit rock bottom. I wanted to kill myself. I couldn’t feel anything. I couldn’t leave the house. I’d forget things and then I’d denigrate myself for forgetting.” Anne petitioned for
deferrals of her courses, some of which she completed that summer and some of which she carried over into the next academic year. Since then she has been taking a reduced course load. “If I had rushed through all my assignments, I would have done poorly because my head just wasn’t there.”

Since Anne’s hospitalization in 1994, she has engaged in psychotherapy. “Therapy has really helped me, even though it’s stressful and confrontational. I have been able to work things out through therapy.”

Anne sometimes thinks that she has an “imposter syndrome” and wonders if her therapist thinks that she does not really have a problem and that she is just making it up. When she required an academic extension, her therapist wrote her a letter saying she was in therapy. Because he did not write explicitly that she should be given a deferral, Anne said she felt that her illness was not “legitimate.” She also sees her uncertainty as related to the stigma of her depression:

If it’s not biochemical, you think it’s just you. You wonder if you caused it yourself.

I think it’s almost more stigmatizing if it’s not biochemical because it implies that you have control over it. I don’t know where my depression originates from. I’m not sure if it is early childhood learning or if it is biochemical. It runs in my family quite strongly. Maybe it is both.

Anne has always been inclined to regard depression as genetic in origin. Her departure from a seven and a half year long relationship with a boyfriend, however, has led her to give credence to what she terms the “social aspects of depression.” This component, she believes, is linked to her family members’ styles of relating to one another and their affect on how she thinks about herself. When Anne is with her family members, she says she starts to doubt herself because they set high expectations and are critical of her.
Anne speaks to her mother quite regularly, but she does not feel emotionally supported by her on a consistent basis. She says that it is emotional support from her friends that has pulled her through her difficulties. Her network of friends do not attend the same university as she does. Anne has one especially close friend, who is studying abroad on a Commonwealth Scholarship.

She really does wonders for self-confidence and she's really helped me because of what she has achieved. She is a sexual abuse survivor and has done phenomenally well. She's been able to succeed against all odds. She let me know that I could do it.

**Nature of the Illness**

Anne states that she has a clinical understanding of her depression. "I have an in-depth understanding of it in an intellectual way. I’ve read a zillion books on it. Sometimes I try not to think about how it affects me in a personal way, on an emotional level because it is too painful." She views her illness as "something that really affects my mood. I’m not sure how I am going to react to things. Sometimes little things really set me off and I become really sensitive to everything."

Anne describes a qualitative difference in her ability to cope with stresses when she feels depressed.

Little stresses that most people can deal with effectively (maybe they feel stressed out, but they can deal with it) make me really physically ill. I get really really stressed out about things, just everyday normal stresses such as finding a summer job, working on a paper. If I’m really bad, something can take me off guard, like losing a wallet or not being able to find something. I get really really upset.

When Anne feels "really really down," she starts thinking about killing herself.

Even when I’m feeling relatively normal, these thoughts cross my mind, that maybe
I should kill myself now and not worry about anything anymore. I guess I have felt like that since I was 14 or 15. Even in my first and second year where I didn’t go through any severe episodes, I would say June of each year. when I finished school and I would be looking for a job, which is very stressful. then I would get really really down and be crying all the time. But it would only last six weeks. and then as soon as things started going better and I had a job and I could occupy my time. I would feel better.

Anne sees a “normal” person as someone who is “able to get by without being too stressed about things. Maybe they’ve been through something like the death of a grandparent, or a parent became ill. They’ve had some sort of trauma, but it’s not multiple.” Anne thinks that even when she is “normal,” she still “registers as clinically depressed.” She recounts doing a Beck Inventory Scale of Depression in her psychology class and scoring quite high at a time when she was feeling “relatively normal.”

**The Impact of Anne’s Illness on her University Education**

Doing course work and writing papers can be stressful for Anne. There are weeks, even months, when she cannot concentrate and focus her attention to read or think clearly. “I have good days and bad days like most people, but usually with me it’s not days, it’s weeks or months where I can’t concentrate, where I’m not focusing.” Alternately, Anne has been driven in her studies. often to the detriment of her physical and mental health. She can be so immersed in her studies that she becomes “almost hypomanic.” At these times. she “pounds out school work and then collapses into a depression.”
When Anne is in a depressed mood, she has difficulty leaving her house and coming to campus. "Just the physical act of getting on the bus and travelling for an hour and a half is hard at those times." Despite these perceptions, however, she makes every attempt to get to her classes, reasoning that it is better to arrive late than not to attend at all. Although Anne is a very active participant in classes when she is well, at times dominating discussions, during periods of depression, she becomes quiet and afraid to speak.

Anne states that she tends to focus on her weaknesses and that she has a difficult time believing in herself. "I also have a lot of trouble figuring out how I am perceived by others." To prove to herself that she is okay, she feels that she has to be "really exceptional."

**Supports on Campus**

Anne reports that most of her professors think highly of her and tell her that she is "graduate student material." "They believe in my abilities. I don’t know why." Anne wonders whether she would be perceived differently by her professors if her marks were not as high. Only one professor, initially, made depreciating remarks about her depression. After he received a letter from the counselling department advising him of her need for academic accommodations, however, she said that his behaviour changed and he took her more seriously. "All of a sudden it was bona fide." Anne thinks that all professors should participate in a seminar on differences where they are made aware of their attitudes towards disability and how their attitudes affect the students they teach. She believes that individuals with psychiatric disabilities are more stigmatized than students with physical disabilities because of the hidden nature of the illness.

Anne finds that "when you aren’t up to dealing with them," academic procedures such as deferrals and petitioning processes are difficult. "Especially with depression, you don’t think that
you deserve it and you don’t think you are going to be accepted. that they are just going to laugh at your petition and say that you should have done better.” She struggles with the ‘special’ concessions that students with disabilities receive. “Are you going to be stigmatized again because of a special group? Are you going to witness backlash from other students who also have stresses?”

In her final year of undergraduate studies, Anne expressed concerns regarding disclosing her illness at the graduate level. “How much should I say to my supervisor? Should I not say anything until I have problems, or should I warn him or her that I have a problem, and if so, will that affect the way that I am treated? Will I be discriminated against?”

Managing the Illness

During her episodes of depression, Anne has difficulty making use of her supports on campus. “I don’t feel like I deserve them, or I worry so much about my work that I stop going to them.” She states that, although during such periods she would have benefitted from the peer support group for students with mental illness on campus, she only attended sporadically. Similarly, she withdraws from her friends off campus and does not phone them when she is feeling depressed.

Anne sees herself as a dichotomist, “either everything is within my control and I blame myself for everything, or it is out of my control.” She is learning “moderation” in therapy. In between the first and second interview, when Anne left her long-term relationship, she reported that her sleeping and eating patterns became more regular. She began to take care of her own needs and was feeling less driven. Her therapist was helping her to manage her illness and achieve more insight into it. On a recent visit to her maternal grandparents. Anne became aware of how her role of ‘sick’ person has been ingrained intergenerationally into the family system.
Most of my therapy happens outside the session. I think about what I talked about and I put the pieces together for myself. I realize that in my relationship with my boyfriend we both didn’t like ourselves, and we abused each other the way our families did. The only way that I can learn to manage the illness is to learn to like myself and break the cycle of abuse.

Anne believes it is important to be aware of one’s “peaks and declines” as much as possible and not to ignore them. “to pay attention to yourself when you need some time. It all comes down to self-awareness.” While she prides herself on overcoming her evidently difficult background. Anne views her life as having been crisis driven and out of control. She no longer wants her life to have that “chaotic” quality. “I need to have a greater perception of control over my environment. rather than feeling everything is happening all at once. Before my illness was running me: now I am learning to accept it as part of me without completely identifying with it.”

Anne recommends that other students avail themselves of supports both on and off campus. She advises them to disclose their difficulties to their professors and to let them know that they are seeking help. “If you are seen as doing something about your situation. I think professors are more likely to support you.” Disclosing to professors, Anne thinks. helps pave the way for any accommodations that may be required. “If you are honest with your professors they know where you are coming from and you are showing them that you are working on the problem.”

The Meaning of Anne’s University Education

I’m not quite sure how my education drives me. I think that I have to keep busy. that

I have to keep my mind working. otherwise. I just sit and think about myself too much

and get depressed and feel down. Maybe it’s because I feel that to prove something
to myself. I have to be really exceptional, and if I can get through this, in spite of everything, then maybe I will feel good about myself.

Anne came to university for “a good job and good money.” She sees her depression as an integral part of her education in that her life circumstances - her personal experiences with major depression, drug addiction, sexual abuse and AIDS - moved her in the direction of psychology. “Psychology helps me understand my own position, studying something that has really coloured and shaped my life.”

When Anne is feeling particularly depressed, university provides her with a way of keeping her life together. “my sense of composure and what I have to do with my life.” It provides her with “safety and structure.” At those times, she needs to get out of her house and have as much routine in her life as possible. School keeps her busy. “I have to keep my mind working, otherwise I just sit and think about myself too much and get depressed and feel down.” Anne is now seeking a better way of managing her life. She presented a shift in her personal growth between the first and second interview five months later. She said that the interviews helped her articulate how she felt about depression, and that, while it is part of her, she does not totally identify with it.

When you do an in-depth interview like this, you start to process things. You figure out what the meanings are for you, even if it’s not on a conscious level, more a subconscious level, in this case education and the illness. Then I guess you start doing something about it. I am seeing changes in my behaviour since the first interview. I’m not quite as driven. I’m not thinking of my depression in terms of personality dysfunction and that I am weak, or whether it is biochemically or environmentally based anymore. I have this depression, whatever its origin, and I
have to deal with it. It doesn’t mean that I’m a sick victim, who doesn’t have control
over myself.

Anne hopes that by accepting and managing her depression, she can balance her keen interest in
academic pursuits and her illness, so that neither rule her life completely.

**Doug**

*You really have to take control of yourself and your treatment if you hope to get
better. For me, education is an important way of being able to do that, of giving
yourself the tools to try and see yourself and your illness in different lights.*

**Educational, Personal and Family Background**

Doug, age 24, comes from a family of professionals. His father is a dentist, his mother a
former nurse. His younger brother attends university and his younger sister is expected to follow
suit. “University education is an important goal for my family. It’s a sign that you have
accomplished something.”

Doug was diagnosed with a learning disability in grade school. “The learning disability
interferes with my ability to organize myself and produce papers.” Throughout most of his years
of high school. Doug had seen a private psychologist for support concerning his learning and
emotional problems. His parents became increasingly frustrated by what they viewed as his lack of
progress, especially since they had invested a substantial sum of money in private therapy.

When Doug began university in the fall of 1990, he was reassessed at the university’s
Learning Disabilities Program and was informed “that he did not meet the criteria for participation
in their service on campus.” He was referred to the support service for students with psychiatric
disabilities. A referral was then made to the university’s consulting psychiatrist affiliated with the
counselling services on campus. It was this doctor who diagnosed depression and an obsessive compulsive disorder (OCD). Although Doug and his family had a difficult time accepting the diagnosis, in retrospect, Doug found it helpful to be told. "I didn't see it as an illness, until Dr. C. told me what it was. I used to think it had to do with my personality." Doug says that it is still difficult for him to accept his diagnosis on an emotional level and that he continues to attempt to deal with that aspect of his disability.

Doug earned his B.A. in five years, while living at home with his family. He was interviewed on four separate occasions between the first and sixth month after he graduated. His interviews differed from those of other students in this study in that he was reflecting back on what he felt he both had and had not achieved while at university. Doug believes that he learned a great deal at university, mainly about himself. "Much as I complain about it. I can't estimate the benefits I have also attained by being here and they are kind of hard to quantify."

Not feeling emotionally supported by his family in terms of his illness, Doug perceives that they see him primarily as "lazy and unmotivated and not doing much of anything." Instead of helping him to address his problems, they become extremely frustrated by symptoms of his condition such as repetitive behaviours. "My OCD and my moodiness frighten them. They worry about what I'll be able to do with myself if I have these problems, how I'm going to support myself. It just concerns them greatly." Doug is highly sensitive to his family's response to him. "I wish I could be the prodigal son. It's very depressing always to be thought of as somebody's problem." He is also aware that his family has had to bear the brunt of his problems. Like them, he wonders about his employability in light of his periods of nonproductivity. Although Doug describes his
educational path as a "long, hard uphill climb," he wanted to prove to his family and relatives that he was capable of graduating, as he perceived them doubting his ability to do so.

While at university, Doug made "some terrific friendships." He recounts how they went canoeing and attended social and cultural events together. Some of them even taught him how to cook. While a student, Doug also held temporary part-time jobs. Although they were not instrumental in helping him explore a vocational path, these jobs enabled him to become more independent financially.

**Nature of the Illness**

Doug describes his depression as resulting in his being "emotionally overwhelmed by life stresses." "A lot of the time I felt things were bleak. I had trouble looking at things positively. I was very pessimistic. This went on for months." Doug feels that most people who are not depressed have difficulty understanding what it is like to be depressed. "We all go through periods of feeling down. The significant difference was the length of time, the severity of the symptoms, and the degrees to which they interfered with my functioning."

As a result of his obsessive compulsive disorder, Doug spent about six hours a day in compulsive behaviours. "You get the feeling that you have to do these things or something bad will happen. There is nothing rational about it. This makes the physical aspect of coming to school or anything in my life difficult."

**The Impact of Doug’s Illness on his University Education**

Doug’s depression interfered with his ability to think clearly, to put ideas together, and to concentrate on his studies.
I had trouble sleeping. Either I couldn’t sleep or I slept too much. I had trouble concentrating. That meant I had trouble reading, writing, and sometimes following conversations... When you are depressed, you have problems understanding things. You are just not thinking properly and that can make the university experience very difficult. You are not on your toes and you have trouble inputting, processing, and outputting the information. That just makes the experience all the more difficult. It’s harder to concentrate with what is going on when you are so depressed. It interferes with your ability to think and do the essays.

When, due to his obsessive compulsive disorder, Doug had to write things over and over in class, he would cover his notes because he felt very “embarrassed, ostracized and ashamed.” “I felt that I should be in kindergarten.” He disparaged his handwriting as well as the written quality of his work. These feelings had a negative impact on Doug’s self-esteem and his willingness to work with other people. “When you aren’t functioning, you start feeling that you are just not smart and then you get more depressed and it spirals.”

Doug found it necessary to take breaks every 20 minutes when doing his homework, so that it took him four hours to do one hour of work.

Sometimes, with OCD, just trying to write an introductory paragraph would be an impossible task. I would get to the second sentence and I would have to do some bizarre ritual. By that time my concentration would be shot and whatever I had before in my head was gone. I would then have to start over again to try and formulate the thought I was thinking.
Doug did not find the academic material difficult. His organizational problems, however, resulted in his feeling overwhelmed by the amount of information he had to digest. "So many things had to be done that I couldn't always handle it and I found that I got backed up a lot." These feelings further exacerbated his depression. "The problems I had in class made it harder for me to digest all this work and then I got very frustrated and I found myself getting very depressed, and then I started having a lot of problems with OCD." Doug's problems interfered in such a global way with how he functioned academically, that there were periods of time when he was not able to do any work at all. "I had to sit down and wait it out." His longest cycle of depression while he was at university lasted seven months. Doug feels that most of the time he was playing "catch-up." Although he has no clearly defined long-term goal for himself, he sees himself, nevertheless, as "just as smart as anybody in medical school." for example.

Doug's illness prevented him from getting to many of his classes, and he was often late when he did attend. "When you can't get to class you can't learn, and when you arrive late it's hard to settle down and concentrate." The repetitive behaviours of the obsessive compulsive disorder (e.g., opening and closing doors) sometimes made it difficult for Doug to get to school. "I would check things, repeat things, which made the physical aspect of coming to school or doing anything in my life difficult."

When he was depressed, his self-esteem plummeted, interfering with his ability to approach people to ask for help, precisely when he needed it the most. Sometimes Doug thought that he should not be at school. He felt that it was hard for people to understand why he would have to do "funny" things in class such as get up and down from his seat or pick up something and put it down 20 times. "They think you are kind of weird. They think that you are less of a person."
Supports on Campus

A great deal of Doug’s learning at university took place on “informal levels.” He took full advantage of the informal social support networks on campus such as extra curricular activities and informal discussions with his professors and peers. These impromptu gatherings, after class, often occurred in the pubs on campus. “Most of my education was outside the classroom. I think most learning goes on in informal settings like that. That’s where you trade ideas, apply what you learn in class to contemporary issues.” Doug said that he learned to socialize at university “more than in any other environment I’ve ever been in my whole life. Other people showed me that there were other ways of being, besides depressed all the time.”

At university, Doug found it difficult to take advantage of the formal supports such as training in learning skills, and being given extra time to write examinations. He attributes this, in part, to his depression, and to the obsessive compulsive disorder that sometimes resulted in his not being able to get out of the house. It meant late arrivals on campus and many missed appointments. In addition, he felt it was also due, in part, to his ambivalence about asking for help. “the shame and embarrassment” of not thinking that he deserved the support.

Doug had a difficult time advocating for himself. “When you have a mental illness, you have trouble fighting for yourself. Sometimes you don’t feel like it. You feel you want to crawl into a corner and hide.” He wrestled with how much to disclose to his professors. He still questions whether he did the right thing by telling some of his instructors that he has an obsessive compulsive disorder, debating with himself over the usefulness of the label. He regarded asking for help as requesting an advantage over the other students.
The overcrowding on campus, which resulted in Doug's inability to get into some courses, frustrated him. "It's a huge place, an impersonal place, and this is true for all students. It is particularly hard for mentally ill people, who are already feeling a little bit isolated and socially insecure."

Doug was also dissatisfied with the lack of coherence in academic programming and the poor academic advising he received. He feels he would have benefitted from a mentor relationship with a professor, who could have advised him on courses to take in his field of study. He would have liked a more integrative academic program for himself. He was also dissatisfied with the teaching style of his professors and how they related to him.

There have been some professors whose attitudes have been I really shouldn't be in school if I can't hack it, if I can't perform like a normal student. I always thought that was ignorant and an unfair viewpoint. It's sad that very intelligent people feel this way, but unfortunately sometimes people get stuck in their own little world views and they have trouble seeing what it's like for other people. When a professor understands and is patient and treats you like a person, it goes a long way to making the experience a lot more productive.

Doug saw me in my working role outside of the research as someone who could help him negotiate the system, as well as someone to "listen" to his personal problems and be "encouraging." "If you don't have someone to talk to, sometimes it makes you feel like the problems are actually bigger than they are."

Doug found that deadlines were "like death" for him. "I hate them because I am not organizationally inclined." Although he thinks that there has to be some kind of deadline for
 assignments, he thinks that there also has to be some flexibility in the system for people like himself, who do not function well under the existing procedures.

**Managing the Illness**

Doug would often swim and do other forms of exercise in order to manage his depression. Generally, he had a difficult time managing his illness. "I was managing it two fifths of the time." He was unable to adopt time management and organizational strategies suggested to him, to assist him with his academic work. He himself states:

> You can teach a person all the skills in the world, but if he doesn’t implement them, then that’s his problem...I never asked to have an oral exam because I am so disorganized that by the time I realized that there was an exam coming up it was too late to apply for extra time, and this more or less has been the story of my life.

Doug slowly learned to come to terms with his illness. "If you accept that you have a problem, that it’s not you, that you are a smart person, that you are worthwhile, then that goes a long way in dealing with it." It was not until a late stage in his studies that he accepted a reduced course load and began not to enrol in early morning classes, for which he was unable to wake up on time. In retrospect, Doug remarked that he would have paid attention better in class, if he had sat in the front row. However, often he arrived late and felt conspicuous and seated himself where he felt he would not be noticed. Although it was suggested that he tape record his lectures, Doug was reluctant to do so. He felt that his obsessive compulsiveness would result in his stopping and starting the tape, though he never tried this strategy.

Doug had no specific direction in terms of his education. His lack of goals compounded his difficulties and made it much harder for him to remain motivated. "If you don’t have a direction,
you are in big trouble. If you are questioning who you are and what it is you want to do here, it is going to be really hard for you to get a lot out of the experience.” Doug contends that students who come to university with a clear idea of what it is they want to do get out of the experience will probably get a lot more out of it than students without defined goals.

Doug did not engage in treatment with a therapist until the very end of his studies. He attributes this delay to long waiting lists and his inability to find someone whom he felt could actually help him. He pursued this route more vigorously only as he was getting ready to graduate. He was the only student in this study who was not under the care of a mental health professional in the community.

Since seeing a cognitive therapist, Doug has recently been able to say that his obsessive compulsive disorder is “a minor inconvenience.” instead of his main obstacle to getting on with his life, and that he is learning to manage his illness better. He now realizes that “with a good strategy you can go a long way in helping yourself as opposed to just letting the illness take over.” He has come to value the importance of “taking care of external problems by getting counselling outside of school.” While he wishes that he could hit on the “magic formula” that would allow his depression to disappear, Doug also knows that, when it does return, the best approach will be for him to cope with it as best as he can and “not take on too much work.” He is hopeful that he will find a way around his illness so that he can extend his periods of productivity and be able to pursue an interesting career. He says that if he is ever to return to university, he will have to have his illness under control.

Doug is currently trying to understand what aspect of his problems is the illness and what aspect is how he himself manages it. Since he has been feeling this way for so many years, he thinks
he needs to distinguish between "what a normal state is and what a depressed state is." Doug believes that people in society view individuals with mental illness as having a failing and a defect in their personality. "that they could not tough it out." He is learning to fight stereotypes that he himself has internalized.

Doug had a great deal of advice to give to other students with mental illness:

You have to persevere. You have to see your illness as an illness and see your problems as symptoms of an illness, not as personal deficiencies. You have to have a goal that you are working towards. Don’t bite off more than you can chew. Keep a good mental attitude. Get treatment. Don’t give up.

The Meaning of Doug’s Education

*It helps to be around normal people. It’s just therapeutic. It’s something I can’t really describe. A lot of the time I felt that when I was really depressed or when I was having trouble with OCD, that the example of alternative ways of being was very important. It served as a bit of a life line, knowing that there were other ways of doing things. Even though university is an institution, it helped in that it showed me what is possible. A lot of the time when I am depressed, I get trapped in this way of thinking. It’s very hard to see beyond the immediate feelings of despair. It helps to know that there is a possibility of other ways of living your life that are better.*

Several factors influenced Doug’s reasons for pursuing a university degree: family expectations, a sheer love of literature and the arts, the intellectual climate, a better quality of life, better employment and an opportunity to explore himself. Doug’s psychology and English courses provided him with an opportunity to re-examine how he looks at himself. “what depression is and
how it interacts with my life.” More specifically, Doug sees his education as helping him understand his illness and its treatment.

You learn why the medical models of mental illness are the way they are. You can help yourself by knowing what treatments are available, by learning how the medical community views your problems and what its ideas are of what your problems might be. Having known that, you can better help yourself. You are going to be able to direct your healing yourself, in terms of the methods of treatment that are out there. For Doug, “education is empowerment.” It provides the tools to improve self confidence.

What you are learning is how to think, how to do research, and how to put thoughts together. It helps to improve the mental tools by which you approach life. That way you can distinguish the weak foundation from the genuine article.

The development of Doug’s critical thinking skills helped to play a role in his taking charge of his life and in his seeking an appropriate and beneficial treatment approach for himself. He thinks that he would have functioned much better at university had he received proper therapy at an earlier stage in his studies. In our fourth and final interview, we both agreed that he had moved from a position of learned helplessness to one of efficacy.

Mark

*My social worker tells me that one of my good characteristics is that I am able to let things bounce off of me and to keep going on instead of putting myself into a rut and into a depression. I have that skill of saying this is my illness and this is me, and I still have a life. I can still communicate and I’m not paralysed. I say to myself that it could have been worse. You just let the rain run off your shoulders and continue.*
Educational, Personal and Family Background

Mark, age 24, comes from an educated family. His father has both a law degree and a masters in education. His mother is a school teacher. His older brother and younger sister are university educated. His sister will be graduating a year before Mark, from the same university. “Education was totally engrained in me since I was in public school. It was assumed that I would get a B.A. and do a graduate degree.”

Following graduation from high school, Mark began university out of town, in the fall of 1990. He returned home in March of his first year. He knew “something was wrong,” but attributed his stress to the hospitalizations of both his grandfather and a former girlfriend. His grandfather died shortly thereafter. Unable to write his final examinations, Mark had to repeat his year. He returned to the same university in the fall of 1991. One month into his studies, he had to leave again, when, he says, his mental illness “kicked in.” He began to experience episodes of agitation and paranoia, and believed that people could hear his thoughts. “I cried a lot. I felt like my insides wanted to kick out of my body and I just wanted to scream.” He visited the emergency departments of several general hospitals, none of which would admit him. Frustrated with the medical system and realizing that his condition was deteriorating, Mark told his parents that he would be better treated at a psychiatric hospital, where he was indeed admitted for several months. When he was first hospitalized in November of 1991, Mark had to put any thoughts about school on the “back burner.” “All I could think of at the time was how I have to get better.” He was diagnosed with schizophrenia and had several hospitalizations for the next couple of years, the shortest stay of which was six weeks.
Prior to returning to university, Mark went to a community college. On his own initiative, he took a night course to help prepare himself for the transition back to school. He began attending a local university in the fall of 1992.

Mark resides with his parents, whom he feels are very supportive of his education. He perceives them viewing his present course of activity as precisely what he should be doing. When he has had a difficult day on campus, he finds "emotional stability and comfort" at his home. "I am not going to my house. I am going to my home." He does not experience any pressure from his parents to complete his degree quickly or to achieve certain grades.

Mark shares information about his illness with his family on a "need to know basis." With respect to his education, they will know when he has an exam or a test and wish him luck. He will not go into detail and tell his parents everything, for example, if he had a difficult time at school because he had intrusive thoughts in class. In part, he feels that it would worry them.

The philosophy in my home is, if I approach them they can probe, but if I don't approach them, it's hands off. I only tell them when something is on a larger scale, if I need to go to the hospital.

Mark views his illness and his well-being as his responsibility and the responsibility of the staff at the hospital where he receives treatment. For instance, if he comes home early because he had to leave class prematurely and perceives that his father is annoyed with him, he interprets it as his father not knowing how to react to the situation, rather than to him per se. Mark has the insight and maturity not to take his father's responses personally.

My mom is more supportive than my father because she is the emotional part of the family. I have nightmares sometimes and I scream in my sleep. She comes in to
help me out. My mom is more of a caregiver. The last couple of years my dad's been a lot better in this area, which is really neat.

The support he derives from his parents, his grandmother and his girlfriend, Mark believes, motivates him to pursue his studies. "the fact that they say if you can't take that many courses, that's okay, you'll eventually get there." Mark uses his "hospitalization free" period of two years as another yardstick by which to measure his success. He also realizes that his motivation comes from within himself, from his internal drive to achieve.

Outside of school, Mark keeps himself busy. He has a strong peer support network including many friends from high school. He plays basketball once a week with several of them. However, he does not regard them as understanding his illness. He finds that sometimes they do not know how to react around him and he wonders if they think that he will blast out in anger. He realizes that he and his friends have different perceptions of the reality of his symptoms. For Mark to believe that his friends truly understand, "they would have to understand that what goes on for me in my head is real to me, so they wouldn't say it's just in your head, forget about it." Other than his girlfriend, his family and the professionals whom he sees, Mark finds that most people do not understand mental illness.

Mark has a part-time job as a support worker at a group home for adults who are developmentally delayed, one of whom has schizophrenia. He has not let his employers know that he has a mental illness. "I'm too afraid to tell them. Society doesn't understand what mental illnesses are." Though he thinks that the people who hired him would likely understand, he would not take the chance of disclosing his illness.
Although his psychiatrist tells him that he places himself in highly stimulating situations (e.g., basketball games), and that he takes on a lot of tasks (e.g., schoolwork, a psychology course where schizophrenia is discussed, a part-time job). Mark feels supported by his doctor’s assurance that he can handle all of these situations. “Every time I take on a new project, he says that I am a glutton for punishment.” He believes that his doctor is proud of what he can accomplish and has told him “if you can keep doing it, go right ahead.”

Mark sees a social worker at the hospital once a week. He says that she is a good listener and he perceives their meetings as an outlet for “anything that comes to mind.” “We speak about education quite often. We talk about my goal of becoming a social worker. She too agrees with my psychiatrist, that I take on challenging tasks, but they back me up.”

**Nature of the Illness**

Mark describes his illness as follows:

It’s like having pictures flying around in my head and sometimes thinking that this person is talking to me, that’s my reality. It is an emotional roller coaster from hell because it is a very up and down type of thing.

One of the reasons Mark has difficulty conveying to significant others (e.g., members of his family or his girlfriend) that he is not feeling well, is that a half hour later he can feel fine. “What happens is that it lasts longer with the people I tell, as opposed to me, where it hits my shoulders and runs off. Then I start to be the care-giver of the other person.”

**The Impact of Mark’s Illness on his University Education**

Mark’s short-term memory has been affected since he became ill. The memory loss, his
paranoia and anxiety interfere with his ability to retain information and to concentrate. All these factors are “what has made the road a little harder” for him.

Both large and small group situations are difficult for Mark. Sometimes he experiences anxiety attacks in lectures and tutorials. In lectures, his paranoia can lead to his thinking that there is hidden meaning in the professor’s remarks. At these times, he may take medication sublingually to help him relax. “Even with medication, it’s very up and down. I can look at the professor straight in the eye and say, okay, but then, five minutes later I think he’s saying something in regards to me.” When his medication is not effective, Mark has to leave the lecture. In tutorials, he tries to calm himself down so he will not have to leave. “I isolate myself in the group or I’ll sit my head down looking at my paper. otherwise the paranoia and the mental illness all snowball.” Mark uses self-talk, saying “just relax, take it easy.” When this method does not work, he has to leave the tutorial because it is “too stressful.”

Outside the class situation, Mark’s social interactions are affected by his moods. “If I’m not feeling well, I don’t talk to anyone. I have my head down.” At these times, if he sees someone in the hall, he will walk away. “I go pick up a telephone and pretend that I have to call somebody because I just don’t want to talk to somebody.” Mark uses this approach as a way of reducing his symptoms. “I’m afraid that the symptoms could get worse because of the interaction.”

The friends Mark has on campus include some individuals he knew before coming to university and some he met in his classes. When he feels well, Mark socializes more and often eats lunch with his friends. “For the most part I know a lot of people.”

**Supports on Campus**

Mark tends to utilize the instrumental supports on campus for students with mental illness:
for example, formal letters identifying his specific learning needs to his professors, writing his tests and examinations separately, and having extra time in which to write them.

He has encountered both professors who have understood his circumstances and those who have been less accommodating. He is concerned about letting his instructors know why he might have to walk out of class, for example, because of an anxiety attack. "I’m afraid of the consequences. I am just afraid of people’s reactions, that's the bottom line." Disclosing that he had an anxiety attack makes him "feel worse" and decreases his self-confidence. If an instructor shows interest and Mark gets to know him, he will divulge information.

Generally, Mark finds that his classmates, his friends and his professors do not understand mental illness. He is reluctant to let his peers know about his illness. He believes that their attitude is that people with mental illness are "abnormal and crazy." "You see ignorance everywhere." He cites an example of a student in one of his psychology classes making "some ignorant comment about what schizophrenic people are like and that they are all violent." Mark felt that the professor did not correct her assumptions and made light of the student’s comments.

Managing the Illness

Mark regards the maximum course load that he can handle as two or three courses. Anything more is "too much stimuli for my brain" and increases his stress. If the amount of work is too heavy, he knows that he cannot deal with it. "It snowballs into I can’t do this and then I don’t know what to do. Then the anxiety comes and then it just gets worse after that. So that is the difficulty." He attempted a summer course but found that he could not handle the tutorials. He tried three classes before he decided to withdraw. engaging in positive self-talk to support his decision.
I have been going through since September. It hasn't been such a great year at all. It's been pretty rough. Why put myself through the stress of a summer course where it's compacted into eight weeks when I have a problem with it for eight months?

Mark's illness and his schooling are intertwined.

If I have a good class, I'm usually in good health. and if I'm in good health, I'm usually quite happy. If I come from a bad exam it affects my health because there is more stress coming from school and I become emotional about it.

Not being hospitalized is a strong indicator for Mark of how well he is managing his illness. "My first hope is not even my education. It is my mental health. I hope I am healthy enough not to be hospitalized." He believes that he is good at setting limits for himself. For example, he is considering taking an additional course. in order to measure his ability to manage extra work without needing to be hospitalized.

Mark's fear of having to stay in university for a long time motivates him to attempt extra work. He has been at this present university for three years and anticipates that it will take at least another year and a half for him to finish.

Sometimes I just look at myself and say. holy cow. she's [a former high school acquaintance] in university already! How can I have a class with her? I was in grade thirteen when she was in grade nine. It's a bit discouraging in that way. I should not be like that. It should be that I'm at university and I'm doing my thing and who cares about them. But it's kind of weird once in a while seeing them. My sister is only three years younger than I am. It's okay with her. but people who are
two or three years younger than her who may have fast tracked through high school.

I say, oh boy!

His advice to other students with mental illness is to speak to their professors and teaching assistants and to make use of the supports that are available to them. “It is important to talk about your problems and your education and that includes talking to yourself.” He believes that it is important to let instructors and assistants know if there is something that should be brought to their attention. “They can help you a lot more than if you don’t say anything.”

The Meaning of Mark’s Education

My illness is a hindrance on the one hand and it’s also the opposite. On a day to day basis you have got to go through it, but it also helps because it makes you want to get through something and capitalize on having an education. That keeps you going and saying, “I think I can. I think I can.” even if I have this. It pushes you forward a little more.

Coming to university is a way for Mark to achieve his independence. He values his self-sufficiency. His mental illness makes him want to “become even more independent.” He views earning a degree as providing him with the confidence he needs so that he can “feel proud” of himself. Mark wants to pursue a social work career, which he anticipates will not only provide him with an income so that he can fend for himself, but also with a field of work that he truly enjoys.

Mark knew the educational path that he wanted to pursue ever since he was in high school. “I liked the sociable caring type of person who helps others.” Since he developed schizophrenia, his desire to help people “grew stronger.” He considers that when he has needed the help, people were there for him, “psychiatrists, nurses and social workers.” “It’s just something special. They’re
helping me to achieve my goals." Having been through the mental health system, Mark feels that he understands what people who are mentally ill experience. "I can see how people can be hurt by the system."

In order to achieve his goals, Mark has to monitor his daily stress. "While I am working towards the goal of social work, I am also thinking of just getting through the day to day life of a student with a mental health problem." Mark has not wavered in his educational goals. Even though they are "harder to achieve." he wants to pursue them "even more."

Mary

*I see myself as wanting to get my degree, but it doesn't have to be in a certain amount of time. It will take me as long as it takes me. I just hope I can finish one course at a time.*

Educational, Personal and Family Background

Mary. age 38. spent her public school years in Quebec. She describes having undergone EEGs as a child. "I have been sick for a long time."

Mary is an only child. and the only person in her nuclear family to have pursued a university degree. When she was 12. her parents divorced. and her mother re-married shortly thereafter. Following high school. she worked for a year as an invoice typist at a custom brokerage.

There were a lot of things going on in my life. I just got really sick. I was doing really weird things. I had a blow dryer that I kept returning and buying over and over again. I remember I stood in the corner one day at work asking people what time it was during my lunch hour. I was so severely depressed. I took a whole bottle of
anacin. My parents had to be called back from out of town when the illness became acute.

She was hospitalized for approximately five months, then joined her mother and step-father who had moved to Ontario. Shortly thereafter she spent another three months in hospital. Mary was diagnosed with a schizoaffective disorder. For approximately a decade, from the mid 1970s to mid 1980s, she became involved in the mental health system. She was in and out of hospital many times, participated in various psychiatric retraining programs in the community, and lived in several group homes and co-operatives for psychiatric survivors. It was there that Mary met her husband. He encouraged her to upgrade her high school diploma and pursue further education. In the mid 1980s she enrolled in an adult education program. Mary then applied to a music program at a community college, but was not accepted. As her second choice, in the fall of 1988, she enrolled in a general arts program at university. She was married in the spring of that same year.

Mary plans to complete her degree "however long it takes." She remarks that since 1988, she has only interrupted her studies once, when she spent a year recovering from successful surgery for cancer. To date she has completed five and a half courses.

Though Mary feels that her parents are proud of her accomplishments, she wishes that her mother would offer her more praise and encouragement. "It's hard for my mom to give me compliments or much feedback at all. If you could talk to my mother and let her know that I need some support from her, just a pat on the back." While Mary's husband is her main emotional support, she says that sometimes he is not able to be there for her "because he is dealing with his own illness."
In the community, Mary draws on numerous resources for supports. She attends church regularly and receives pastoral counselling. She meets with a social worker monthly. She visits her psychiatrist every three months to have her medications monitored and has regular contact with her mother, her step-father and her in-laws. She also speaks on the telephone weekly to her natural father, who lives in another province. In addition, she has a support network of psychiatric survivors and a few friends who do not have psychiatric histories. Mary plays an active role on the executive of the subsidized apartment complex in which she lives. A COTA (Community Occupational Therapy Association) worker and a public health nurse visit her apartment, when she becomes depressed and suicidal.

**Nature of the Illness**

Mary finds it difficult to explain her illness to other people on two accounts. In general, she says that she has problems expressing herself verbally. More specifically, it is not easy for her to convey the subjective aspect of her illness to someone who has not lived the experience. “You have to go through it yourself. Like anything else, if you don’t experience it yourself, nobody else can really understand it.” She states that she does not hear voices, providing that her loxapine medication remains at 50 milligrams.

I do hear music a lot. I think that’s because I am musically inclined. I play the keyboard and the piano. I’ve had music ingrained into my mind all my life. I’ll sing a song in my head sometimes. But then I have these bad music days when the same song goes on over and over and over.

Mary can experience several anxiety attacks in a day. At these times, she has to take medication to help her continue her daily activities. She describes her illness as follows:
My illness is unpredictable. It can hit me at any time. It can flare up at any moment. I can do really well and I can crash, and then I get really depressed....It is sort of like a roller coaster because you never know how you are going to feel one day to the next. You never know if you are going to get psychotic or what is going to happen to you. You have to live one day at a time.

**The Impact of Mary’s Illness on her University Education**

Mary’s illness affects both her concentration and her memory. She attributes her problems with memory to the effects of the medications. In consequence, she feels she has to study “a lot harder in order to achieve good grades.”

Mary reaches out to others. She has no difficulty asking her classmates for notes when she has to miss a lecture. She frequents the Mature Student’s lounge where, as an older student, she feels more comfortable. “It’s a bit difficult to break the ice and make friends, especially when the students are younger than you.” She would, however. “never let on” to these mature students that she has a psychological problem, and feels that she has to “watch” what she says. Although Mary has never encountered any actual discrimination, she wonders what people would think of her if they knew that she has been on campus since 1988. She does not think that they would understand the nature of her prolonged status as a part-time student.

**Supports on Campus**

Mary draws support from many areas on campus: social support from the Mature Student’s Association and a weekly peer support group for students with mental illness; emotional support from appointments and more frequent telephone conversations with her educational counsellor; academic support from a learning skills specialist, an academic advisor, her professors and teaching...
assistants; financial support from a counsellor in the financial aid office; and administrative support from an ombudsperson at the registrar's office. She enjoys participating in the peer support group on campus. The interaction with others who share a similar background is so important to her that she makes every effort to attend. Mary also maintains a friendship with a fellow student whom she met in one of her courses. "This woman is always giving me encouragement."

Mary perceives most of her professors as having been very supportive of her learning needs. "Except for one, they've all been very kind. They know if I need extensions that there is usually a good reason. They try to support me when I am going through a rough time."

Mary generally has no difficulty asking for help, but finds it hard drawing the line between her professional support systems on and off campus, "not knowing whom to call about what." Sometimes she wishes that there was a person at the university who was there "all the time" to talk to when problems arise. She believes that if she did not have an on-going illness, she would complete her degree much faster and would not need these numerous supports. "As it stands now, I need all the supports."

The support system in place at this university has allowed Mary to take one step at a time. She has been successful in petitioning to defer some of her assignments and examinations beyond the academic term. She knows that she will not be forced to withdraw because she cannot complete her studies in the time period allotted to most other students.

**Managing The Illness**

Managing her illness is very important to Mary. She measures her own success in this area in terms of her "zero hospitalizations" over the last three years. It means she "must be doing something right."
Although her long-term goal is to "finally get a degree." Mary regards this goal as only possible if she proceeds at her own pace, without imposing a time limit on the duration of her studies. "You can’t rush yourself, because if you do, you could end up in the hospital again." She appreciates the fine balancing act involved in “juggling” school and her mental health. When she experiences a relapse, Mary does not rush back to her course work. She has adopted the attitude that “school won’t run away; it will always be there.”

Students who have been recently diagnosed with a mental illness will learn as I did that it will take longer than they might have expected to get their degree. and they have to learn to live with it.

**The Meaning of Mary’s Education**

*I have been in tons and tons of psychiatric programs. These programs were for illnesses. Education keeps me going. It’s an incentive. It’s a reason to get up in the morning. If I didn’t have school, I don’t know what I would do. I may not be alive now if I didn’t have something to look forward to so much. As a person dealing with an illness, it has given me a chance to be educated, despite my disability.*

Mary finds her pursuit of post-secondary education more stimulating than her past participation in countless “dead-end programs” for psychiatric survivors.

You need a bit of stress and stimulation to keep yourself going. You just have to have something to look forward to. Who looks forward to programs in hospitals? There aren’t many things that you can do with them. My university education gets me somewhere rather than in just a psychiatric rut.
Mary states that the journey along her educational path has been and will probably continue to be "a long haul," but she finds the intellectual and social stimulation challenging. She also regards "having confidence in your achievements" as essential to success and has demonstrated this belief by returning to school after a recent set-back.

Shortly after the first interview, Mary experienced a slight relapse, feeling depressed and suicidal. Five months later, at the time of the second interview, she reflected back on her struggles and was able to see how, in spite of her serious illness, she is doing a good job of managing her mental health and her university education.

I learned a lot about myself from reading the transcript. I learned that I have come a long way, how I struggled, how I'm trying to keep on top of everything, and how I'm keeping my mental health in good shape. You have to deal with the day to day things, because if you take care of the little things, the big things get taken care of.

I am a university student who has an illness and I'm dealing with it as best as I can.

Omer

You can see lifting weights as just a simple activity, but really you are strengthening your whole body. You are being disciplined by going there and doing it, having the confidence to lift it up. In other words, by doing it you achieve many other things as well. In this way, I think that pursuing a university education helps control the symptoms of my illness, if I am capable of dedicating myself to studying.

Educational, Personal and Family Background

Omer, age 40, grew up in South America where he successfully completed his high school education. He immigrated to Canada with his parents and sister a little over twenty years ago. His
father, who died two years ago, returned to his homeland after five years in Canada. He left behind Omer, his younger sister and his mother, none of whom ever saw him again. Omer resides with his sister and mother. Omer’s mother was a registered nursing assistant until she sustained an injury at work about three years ago. In spite of her receiving a disability pension, the family has experienced financial hardships.

When he arrived in Canada, Omer studied English as a second language, and then began night classes at university, in the late 1970s. His eclectic interests led to his taking courses in the arts and sciences. After several attempts, however, he withdrew from classes. He attributes his false starts to several factors: he had been away from school for a long time; his English skills were not sufficiently proficient; his father had left the family home around that time. In addition, he found working full-time and taking night classes too difficult to manage. He had a series of jobs, first as a welder, then as a furniture refinisher, and finally as the floor manager of a plant’s operating machinery, in order to help finance his sister’s education. In 1990, when the last company he worked for closed down, he entered a community college to study computer science. At the same time, he began to be treated at a psychiatric hospital in the city for a number of conditions including an anxiety disorder, an obsessive compulsive disorder, depression and mild Tourette’s syndrome. Omer does not think that he could have returned to university and have made social contact with people were it not for the medication he is taking. “One of the benefits of Paxil is that it increases my self-confidence.”

Omer was one of the top students in his class when he graduated from the community college program and was advised by his instructors to pursue a university degree. He received several credits for his courses at the community college and in 1992 re-entered the same university he had
attended in the late 1970s, this time as a day student. Having read an advertisement in the student newspaper, he made contact with the support services for students with ongoing mental health needs one year later.

Adaptation to change is a difficult process for Omer, and the transition from a structured community college program to the university was not easy for him. He missed attending smaller classes where he knew most of the students and the instructors on a personal level. He finds the size of the university a barrier that contributes to his "increase in depression and sense of isolation."

While Omer's family is his main support, he feels emotionally burdened by his mother's unemployment, her anxiety and her constant presence at home.

She talks a lot and that robs me of time and energy. I feel pressure of having lost time from my studies. She complains about things and that can be depressing. She can be critical of me and she argues a lot with my sister.

Omer's mother also suffers from an anxiety disorder and depression. She has had involvement with the mental health system, but not on a consistent basis. He says that her focus has been worrying about him and that he finds it difficult having her at home full-time. She has limited contacts outside of the immediate family.

Omer feels that his family does not understand his illness. He perceives his mother treating him as though his behaviours were due to character flaws and a lack of initiative. Nevertheless, he describes their relationship as a friendly one. "My mother didn't enjoy getting out of the house much, even when she was in South America. Because of the social isolation and with my sister seldom at home, I am her only social support. She needs me for company." According to Omer, his sister thinks that his mother wants him to depend on her for the rest of her life. "In the morning
when I want to leave, my mother always calls the TTC and checks the schedule for me. If I am running out of time or I am anxious, if my mother doesn’t give me a panic attack, she is kind enough to have one for me."

Omer describes most people as experiencing typical stages of a life cycle: being raised in a supportive environment and cared for by family; being educated in a structured environment that provides a young person with a ready made social milieu and then having these supports wane as one approaches adulthood.

Over the passage of time you’re suppose to start building substitutes for yourself. for example, building your own circle of friends. getting outside support. learning something and getting a job. I get the feeling that due to my problems that I haven’t done much of that....Sometimes I wonder if I’m like Sisyphus or Charlie Brown. because Sisyphus had to push a rock and he was useless and he knew he was useless. but he didn’t have any other choice.

Low self-esteem makes it difficult for Omer to ask for help. He perceives the request for academic accommodations as “getting something privileged and hurtful to my self-esteem.” In addition, he attributes his lack of assertiveness, in part. to family dynamics and cultural norms. He views his mother’s own problems as being heightened when anything goes wrong. “It raises her anxiety level and she tends to catastrophize.” At an early age he learned to protect her. He also attributes this trait to his culture, where, “if you’re a man you are supposed to take care of yourself and not ask for help.”

Omer worries about the poor economy. his mother’s approaching retirement and his own tendency to be socially isolated. Although he recognizes that his illness has both a biological and
environmental component, he sees "many things in his environment that conspire to make it harder" for him. For example, his lack of vocation at his age, his family's financial worries, his illness, his family's lack of understanding and acceptance of his illness and the frequent arguments at home.

**Nature of the Illness**

Omer reports that his present therapist, whom he has seen for several years, regards his symptoms as being related to autism. He can trace his illness back to when he was a young boy in South America. His mother took him from doctor to doctor because he was inattentive and withdrawn. He would often play repetitively with a piece of string and "be oblivious to the rest of the world." Omer tends to feel disconnected from people, but not as much as when he was younger. "Sometimes I feel as if I live in a world of my own and I only partially come out every once in a while for some important matter, where something has to be done about it." He describes himself as follows:

> My mind is a bit like a car, the wheels, the brakes and the accelerator went hay wire.

> I have difficulty making plans, dividing them into steps and going ahead with them.

> At times I want to sit down in a chair lost in my thoughts. Somehow I think I look at the world as a gloomy, foreign and chaotic place.

Omer experiences a lack of flexibility because of his OCD and this restricts his functioning. The OCD chains me to regular activities I do and it is difficult for me to try new activities. I have to do tasks in a certain order. If I have five tasks to do, I can get stuck on task number two and become paralysed. Then I am unable to proceed with other tasks. This means that every time I do something, it's like the first time. I do not accumulate experience and knowledge about the given task.
He reports feeling constantly anxious.

Whatever happens, the anxiety is always there. My OCD aggravates the anxiety. It is like you are in a complete trance, repeating things over and over, while at the other end you are fully aware of what you are doing, but unable to stop the cycle. The OCD can also cause negative thinking and expectations. I catastrophize, and so often, in new situations, I feel doubt. Either I start feeling very anxious or I start remembering times when I made plans and they didn’t materialize.

In comparing himself to other students, Omer thinks that, though they might also come to university without a clear goal, their problems are less intense. “They can work on compensations like achievements, family life, working, having a hobby and a vocation. which are hard for me because I get anxious.”

Omer wishes that he could feel more at peace and less anxious and panicky. He is “always afraid that something will go wrong.” He thinks that if he did not have so much depression he would be happier. Even with the involvement of four psychiatrists, one for psychotherapy, one for drug maintenance, a consultant for treatment of his anxiety disorder and another for his obsessive compulsive disorder, Omer has felt frustrated his whole life. “I never get any resolution to these problems, so it is hard for me to imagine that I will be able to do anything.” He does not believe that he is “ever going to be completely right;” nevertheless, he attempts to “keep that hope and fight.”

**The Impact of Omer’s Illness on his University Education**

Omer does not think that understanding academic material itself presents a problem for him, but has difficulty focusing on his work and adhering to the task at hand. Because he becomes easily
distracted, he is unable to concentrate for an extended period of time. His anxiety disorder also interferes with his ability to study effectively.

When I am trying to study, sometimes the anxiety keeps building and I have to stop. I may start thinking about something else and I can’t remember what I read. When I try to do a task, it’s like part of me is trying to escape, so I sometimes do things by rote without paying attention to what I am doing.

His difficulty with organizational skills and time management make it difficult for him to plan a step-by-step solution to a problem: First, he becomes so obsessed with the steps that he does not pay attention to the task. Second, he becomes depressed by his lack of progress.

I cannot tell myself that today I’ll do this, tomorrow I’ll do that, because maybe today I tried and perhaps I didn’t understand something the first time, and then I start getting depressed.

Frequently late for appointments. Omer may miss them all together. Similarly, he is often late for his classes and his attendance at them is sometimes sporadic. After being absent from several of his classes, it becomes increasingly difficult for him to resume the routine of regular attendance. “I feel some kind of anxiety and resistance toward doing it, as if it were something completely new.”

When Omer is with people, he says that it can be “very socially uplifting.” He believes he needs to socialize more to get out of his depression. Because of his age, he finds the number of younger students on campus a hindrance to his socializing. He does not feel comfortable in large group situations and is more comfortable meeting people in a small structured environment.
Supports On Campus

Omer has found it beneficial to have a support person on campus with whom he can meet regularly. As a result of his having a campus advocate, he “no longer perceives the university as a completely foreign and hostile environment.” Having been introduced to specific contact persons in the academic advising centre, financial aid office and other departments on campus, he now sees that there are ways to work within the system. “Those personal contacts helped in a major way to change my feelings towards the place.”

Involvement in the peer support group for students with continuing mental health needs provides Omer with his primary social contacts on campus. “There I don’t have to pretend that I have problems. I don’t have to cover them up with a joke. I can be more myself.” With several of these students, he also participated in a four day wilderness trip organized by the university counselling department and a non-profit agency in the community. Initially reluctant to attend, he describes the experience as “one of the happiest moments” of his life. “The sense of fellowship that developed with other people, the change in environment, the wilderness itself and achieving the goals of the program” are what stands out for him. “It wasn’t life or death that I climb that wall or do the ropes course, but trying the activity.”

Omer would like to see the university have some procedures in place to facilitate asking for extensions and enabling students with mental illness to get into the courses they want. He would also like to have instructors who are more accessible than the usual one to two hours per week.

Managing the Illness

Omer has placed great faith in his doctors’ abilities to find the right combination of medications to control his illness. He takes large dosages of medications and hopes that, although
not curing his illness, that the right combination of medications will reduce the symptoms to a manageable level so that he can function better. Only then does he think he will be less frustrated and better able to accept his illness. However, he also fears that “by taking medication to control one thing, it will make something else worse.”

While Omer has a good intellectual understanding of his illness (“If I don’t understand, I would be blaming myself for everything.”), he is discouraged by his level of emotional acceptance. He acknowledges the importance of acceptance. “If you don’t accept it, you may try more than you can handle.” Still, he fears that true acceptance will lead to “feeling like a helpless patient.” “My fear is that acceptance is a bit like giving up...I am afraid that part of the little functioning I have is due to force of will and that I am going to lose that too.”

Omer also sees acceptance as related to his self-esteem, which he describes as “shaky.” “If you have a good self-image, it’s easier to accept your problems than somebody who has a low opinion of themselves.” His low self-image affects his ability to communicate openly with his doctors. For example, even though he might have concerns about his medication, he would tell the doctor who monitors his drugs that he “wasn’t doing badly” because “deep down the doctor had a lasting hope that the medication would do something for me.” Although he finds his psychotherapy “a little too vague and unstructured,” he would not discuss his perceived need for cognitive therapy with his psychiatrist. He feels embarrassed and ashamed to say that he is not doing well.

Generally I talk about the good things. If you have a self-image problem and talk about having problems, you feel like other people will think less of you. There is a need to be liked and not perceived as a whiner.
In addition, he resists setting goals for himself. "Either I don’t make any or I make them too ambitious. My insecurity causes anxiety when I try to set goals." With the right combination of medication, relaxation therapy and cognitive therapy, he does not think that the illness would affect him as much. He contends that the main focus of his difficulties are mostly related to his illness.

While there is support at the university, it is because of my illness that I have these problems. Though the system could be better, I don’t see the system as necessarily causing the problems. It may perhaps make it a little bit worse.

The advice Omer would give to other students with mental illness is to understand their weaknesses, while focusing on their strengths, and not take on too much work. He says that they should search out all the sources of help that are available to them on campus, to get to know the system as a whole and what each department does.

The Meaning of Omer’s Education

...It would be good for me, not just in terms of having a degree, but like a person in pursuit of a mystical quest and who, at the end, returns transformed inside.

Omer refers to his general goal of studying computers as the “external” purpose of his education, one that he hopes will lead to gainful employment. However, he finds it hard to envision a future in which he will be able to sustain his efforts to study and achieve this goal. He is more specific about the “internal” purpose of his education, which he likens to a “mystical quest” where the traveller becomes “transformed inside” at the end of the journey. He enjoys the fixed tasks he has to do at university and the routine that he has to follow as a student. “The very fact of having to come every day and sit in the class is very therapeutic.” He looks to his education as providing
a "formal behavioural therapy program where he can become disciplined to do whatever is required" so that this support will generalize to other areas of his life. Using the metaphor of a weight lifter engaging in the activity to strengthen his muscles and better his concentration, Omer hopes that university will help him to "become more alert, more confident, better focused." He anticipates that the activity of interaction with others and the necessity of study will have a beneficial effect on his ability to concentrate. Ultimately, then, he perceives his university experience as providing him with a way of controlling his illness.

Post Script

In September 1995, Omer stopped attending university on a formal basis. After completion of the research interviews, he and I discussed his educational plans. He recognized that he was "going around in circles." He continued to attend the weekly support group until January 1996, when arrangements were made for him to attend a more structured rehabilitation program that focuses on the social, emotional functioning and vocational needs of persons with psychiatric illnesses. Although Omer has always seen his intellect as his strongest asset, he reflects that a program more geared to social adaptation and control of his problems is "more beneficial." "I need to overcome my low self-esteem, practise more relaxation so as not to be so anxious, focus more on the outside world than my inside self and establish more realistic goals." He would like to return to university in the future. Before he does so, however, Omer says that he needs to have a better way of dealing with his problems.

Jeff

At first I was more a schizophrenic than a person with schizophrenia. I have moved from being preoccupied mostly with the results of the illness and what the illness was
doing to me to finding outside interests. Accepting I had an illness helped me make that shift and to take meds regularly.

Educational, Personal and Family Background

Jeff, age 44, comes from a family of "high achievers." His older brother has a PhD as well as a degree in dentistry. His older sister has a masters degree and runs her own business. His mother, who died in 1990, was a professional in the community. His father, who now has Alzheimer's, ran his own "successful" business, though he never completed his post-secondary degree. Jeff perceives his family's goals for his education as compatible with his own. "as a way of being active, for stimulation, and to increase self-awareness."

Jeff was an 'A' student in high school, until grade thirteen, when his marks dropped to a 'B' average. After completing high school in 1969, he entered university. He spent part of his first year living at home, then moved into a campus co-op, in the same city in which his family resided. He had to drop several science courses a few weeks into his first term because he could not understand what was being discussed in lectures. He changed majors and studied English. That summer he travelled across the country visiting with various friends and living as a "wild hippie."

In the fall of his second year, Jeff began living in communes. He had come under the influence of a strong religious personality and joined another faith. His family regarded his radical change of beliefs as an "incredible" transformation. His father has suggested that perhaps this was when his illness began. He returned home on his parents' urgings. They were concerned about him as he was spending most days in his pyjamas and chanting. One week later his parents had him admitted to hospital where he remained for three months. He said that his parents initiated the hospitalization because of his extreme social isolation and not because of his sudden interest in
another religion. "I had withdrawn entirely and wasn’t talking to most people including my parents." No official diagnosis was made at that time. In spite of his lengthy stay in hospital, Jeff managed to complete his second year with a ‘B+’ average. He was relatively stable during his third year.

In 1973, during his fourth year at university, instead of striving for his distant goal of becoming a doctor, Jeff had lost his sense of motivation. Feeling restless and under stress, he says that he was unable to avoid sounding confused in the essays he wrote. In April 1973, he was hospitalized for ten months and placed on anti-psychotic medication. He was unable to complete his final year of his first degree until 1981, eight years later. He describes having been almost completely bedridden in the intervening years. In order to complete the remaining two courses, Jeff said that he had to work for five minutes and then sleep for 55 minutes because of the severity of his illness. During this time he changed hospitals, which he indicated, facilitated his diagnosis of schizophrenia in 1978.

When I heard the doctor say that I had schizophrenia, I said that’s nonsense, that’s completely ridiculous. I had taken introductory psychology and had learned something about it. Though I had no memory of the facts and the science, I had some kind of idea of what the psychological teaching about schizophrenia was and no way...

Over the next decade, Jeff learned to deal with his illness. He took academic upgrading courses for several years and then returned to university as a special student. He also got married during this time. In 1991 he began work on a second degree in environmental and health sciences.
and history. He received some course credits from his previous degree and has one and a half courses remaining towards completion of his second degree.

Having been under the purview of the mental health system since the early 1970s. Jeff is sensitive to psychiatry as an agent of social control. He does not believe in placing "tight controls" on himself as a person with a mental illness. It took several years from his first hospitalization before he began to comply with his doctors' medication regimen, noting his steady improvement. In the last two years, he says that he has only spent 10 days in bed.

Jeff's primary social contacts are with his wife, members of his family and other psychiatric survivors in the community. He is very involved in caring for his father who has Alzheimer's. He and his wife often spend one day a week with his father, who lives in his own home with round the clock protective care. In addition, he is also on the executive of the tenant's association of an affordable housing complex where he and his wife reside.

Jeff meets weekly with his occupational therapist. They are currently discussing his goals once he completes his degree. In addition, he sees his psychiatrist monthly for monitoring of his medication.

**Nature of the Illness**

Jeff describes himself as having two illnesses, schizophrenia and tardive dyskinesia. The latter is a cumulative side effect of the medication he takes to control his schizophrenia and is thought to be irreversible. It causes involuntary muscle movements of his tongue and his limbs.

He states that he does not hear voices, but that he sometimes talks to people who are not physically present.
I’ll be sitting on the couch talking to myself. I may say my psychiatrist’s name and tell her to leave me alone. I’ll talk to her. I don’t hear her talking to me. I’ll tell her to go to hell and say, why don’t you (Jeff) as well.

It’s been 12 years since Jeff’s last psychotic episode. He describes that period as one of total terror, during which time he experienced paranoia, feelings of grandiosity and fear. He still experiences feelings of grandiosity in that he believes that he “fits into the scheme of things in a special way.”

When I feel this way, I think that I can do anything; not that I can stop the subway with my hand or Premier Mike Harris’ cuts. This feeling that I am perfect is interwoven with feelings that I have about the universe. My life philosophy is an ecological one. Every thing is interconnected. When I pet my cat, I feel that I can exercise power over what’s happening in the outside world. I don’t see my life philosophy as part of my illness.

Jeff, in fact, separates his illness from his “world view.” He also feels satisfied with his perspective on life. “I haven’t tried a new medication because while it may take care of the grandiosity, it may encroach on my world view.” This determination dissuades Jeff from trying different medications that might lessen his dyskinesia.

The Impact of Jeff’s Illness on his University Education

Since his teen-age years, Jeff feels that he has had obsessive traits and that his schizophrenia has resulted in his becoming more obsessed with a “search for the truth.” He sees himself as an “idealist and a perfectionist:” “I want to find the truth and express it and let other people know about it. If I don’t, I sort of get upset. If I don’t find it in a class or an essay, I am hard on myself.” He
reports that in the mid 1980s his doctor had considered medication for this obsession. but that he improved. He sees this positive change in his condition as being related to his returning to university.

Jeff's illness affects his ability to concentrate. He can spend hours working at his computer and "accomplish nothing." One symptom of his illness is that he sometimes hesitates to use the computer to facilitate his studies, for fear that it will "control" him.

Jeff does not think that he differs from other students in either his ability or his level of achievement. Instead, he believes that the difference between them lies in the length of time it takes him to complete course work. He sees students spending 10 to 15 hours on an essay on which he may have to spend "100 hours." When he reads a paragraph and has difficulty understanding it, fear overcomes him. "What if it's on the exam? Maybe there's something there that is important?" He says that, although he thinks that most students can overlook the material they do not comprehend and move on, he is unable to do so. "It's like a fear of the unknown. It creates anxiety and a pain in my chest, a fear that I can't do it and why can't I do it?"

Jeff reports that his dyskinesia produces fatigue. "Classes are kind of rough with my dyskinesia and my speech." As a result of his halting speech, it takes him longer to express himself verbally. Also, his arms and legs are in constant motion. Having interviewed Jeff on two separate occasions, I was made aware of just how exhausting it is for him to speak and sit for an extended period of time.

As a result of his schizophrenia, Jeff's behaviour has been altered. He describes himself as being more "boisterous and excitable" in class than other students. He says that he speaks in a louder voice and tends to interrupt when his professors and peers are talking. "I shoot off at the
mouth.” He does not think that he overreacts as much as he used to, but his excitability is still not totally under control. He recounted how in one class, he and another student were vociferous: “Not like parliamentarians shouting out shame shame. Somebody would say something and we would let them know how we felt.” This behaviour was not typical for every class Jeff attended. He especially liked this particular professor and “got carried away by the material.” He reports becoming quite animated about a subject matter he enjoys and that his enthusiasm can sometimes be misconstrued initially as disruptive behaviour.

Both his schizophrenia and his dyskinesia, he reports, can have an effect on his social interactions. His schizophrenia causes him to misread social cues. These misperceptions of social situations can affect his social interactions with professors and peers.

We were watching a film in class where some nuns who were activists in the Woman’s Movement were saying that paganism was an important practice in the Middle Ages. I said, “Isn’t it amazing that nuns would say that?” The professor said that these nuns weren’t necessarily representative of the majority, which I thought was putting me down. I was a bit enthusiastic and I felt that she was objecting more to that than to what I was saying.

Because of his dyskinesia, Jeff sometimes hesitates to go to class “where students look at each other and smile.” He interprets their facial expressions as meaning, “What is wrong with him?” He perceives their nonverbal cues as derisive and feels like a “loner” at times. Jeff tries to change his thinking about the situation by telling himself, for example, that perhaps the students are smiling in appreciation for what he has said or at something unrelated to him.
Supports on Campus

Jeff has not developed a strong social network at university. He describes a relationship with a student he met a number of years ago on campus. After a while, when he attempted to contact this student, the person never returned Jeff’s telephone calls. He admits that it has been “kind of rough as far as the social aspect is concerned.” He feels, nevertheless, that being at university has helped him communicate with people. Although he has not made any close friends at university, his bursary for students with disabilities has provided him with an electronic typewriter and a computer, equipment that he feels has enabled him to “carry on a conversation with a lot of different people.” He sees such instrumental supports, especially the computer, as “opening up conversation.”

At one of my classes, someone said he had a certain computer program. I asked him if he had a Mac. He said yes and I said that we did too. I couldn’t go any further than that. A few of them continued talking. I had nothing further to say. So there is a problem, but I can make contact. At a certain point it fizzled out.

On occasion, Jeff has attended the peer support group on campus. One reason for his sporadic attendance is that he takes most of his courses at the smaller of this university’s two campuses and the support group meets on the larger campus. He has, however, availed himself of many resources on both campuses: individual counselling services to help him deal with the death of his mother, the peer support group for students with mental illness, academic accommodations such as extensions on assignments, deferral of examinations and financial assistance for his disability. When he experiences difficulty with his courses, Jeff does not hesitate to contact key individuals such as academic advisors, learning skills specialists, and advocates who can speak on his behalf. He is not intimidated by professors and readily lets them know the kind of
accommodations he requires. “Professors are quite reasonable if they know you are making a serious effort or even if you haven’t been able to, that you want to.”

Managing the Illness

Jeff says that he cannot manage a full course load. His philosophy is. “If you have to drop a course, that’s okay.” He is not afraid to ask for accommodations and does his work in manageable units. “I take things day by day and week by week.”

In order to manage his symptoms. Jeff uses a variety of other techniques including relaxation therapy, yoga and cognitive restructuring.

Lately I found that I can use my thinking to help me. With my dad, who has Alzheimer’s, I used to say, as my parents said about me when I was first hospitalized. “He’s so sick, he’s so sick.” In my mind I’ll change the channel and say he might be getting better or that’s not all there is to my dad. He’s not just an illness as I am not.

The Meaning of Jeff’s Education

As a psychiatric survivor, there is a tendency to slip into the mesh that is provided for me.

The impression of people is that psychiatric survivors can’t do much and a lot of psychiatric survivors tend to find themselves in that position.

Jeff has no specific goals for himself following completion of his second degree. He and his case manager (an occupational therapist who meets with Jeff to help provide practical support around daily living) have discussed the possibility of his pursuing a degree in library science. If he does not pursue a master’s degree, he is afraid that he “won’t have much to do.” If he continues his studies, he is afraid of having to “lean on” his professors. as he feels he has done all along.
The role of student, Jeff believes, distinguishes him from the “average psychiatric survivor.” “It is easier for them [psychiatric survivors] not to try. For me, it is easier to make an effort than not to. It keeps my mind, soul and body together.” He feels challenged by the responsibilities involved in functioning as a student.

Jeff distinguishes between the “explicit reasons” for attending university such as working towards a degree or a vocation, and his own “implicit reasons,” primarily to keep busy and to have a place to go. “School is a distraction to a large extent. I love reading and going to the library. I enjoy the work that I am doing.”

Jeff’s schizophrenia makes his life “a struggle many steps of the way.” The university experience provides him with a structure and routine, and an opportunity to interact with other students. He has a keen interest in learning and “a desire to improve the situation of the earth.”

Sid

*When I’m in the valleys of my moods, the meaning of university is either nothing at all or a lot of work. a lot of effort in so many different ways. in the reading, the studying, the homework, the actual mechanical work, as well as having to come here, having to be in a classroom, maybe socialize or just being here. In those low periods everything is tough, so the meaning gets lost. The meaning of being here in general is that it can open doors for me. I am trying to maintain as normal a lifestyle as possible, to presume that I am going to get better. Whether I look at my depression as something that can either be controlled or cured, the point is I don’t want to sit around and have nothing to do with it. I’m keeping the doors open for my future by being at university.*
Educational, Personal and Family Background

Sid, age 46, was born in the United States, one of four siblings. His parents encouraged their four children to attend university: all of his siblings, who still live in the United States, have at least masters degrees. Prior to moving to Canada in 1972, he had completed one year of post-secondary education. When he first arrived in western Canada, he studied journalism at a community college. He completed one and a half years of a two year program before being hired as co-editor of a moderate sized local newspaper. In 1981 Sid married. He and his wife separated six years later. After his divorce, he moved to Toronto. Unable to find a similar job in journalism, he took a job with the post office for 13 years, having been a postal worker in the United States. His children, now is their pre-teens, live with their mother in another province.

Sid did not resume his university education until 1990, when he returned to school in the hopes of attaining a better job and career. In the first year and a half of study, he was very successful academically. He was an 'A' student and earned a scholarship, but then had to withdraw from his studies because of his first serious bout of depression. He had two serious suicide attempts for which he was hospitalized, and returned again to university in 1994.

As a child, Sid had been physically abused by his father. Tending to keep his emotions to himself, he had difficulty socializing with others. He indicates that he had mental health problems 20 years ago, but that he did not recognize and see them as problems at the time.

Even though I was dealing with things poorly, things did not affect me as much. I had this inner strength to defend myself against them. I still had the energy of youth. I was still running with a pretty full tank.
Nature of the Illness

To describe his depression, Sid uses the analogy of an "emotional gas tank that is practically drained and that never gets filled beyond one-eighth." With a very low gas tank, any kind of stress can be devastating." His self-perception of being a "depressed person" affects everything he does.

From my perception, the largest aspect of my personality is the illness. It is the biggest part of me. I've come to see myself as a depressed person first, and as anything else, be it student, brother or friend, second. I don't see myself as a computer scientist, a student, or a mature intelligent person. I see myself as someone who is mentally ill.

Sid contrasts himself to the interviewer, whom he views as someone who is "representative of normalcy."

You have the ability to shrug off a negative comment without the arrow going very deep. For someone like myself, who is depressed, it's like there aren't any defences and any kind of an arrow goes deep immediately, so even the slightest things can be devastating, and to try and socialize under those circumstances is very difficult.

'Normal' for Sid is living life without debilitating problems. "an absence of emotional problems that take you out of a normal life style so that you cannot hold a job, you cannot deal effectively with life's problems and be a full-time student." Sid's depression affects his functioning in every area of life. He can remember standing in front of his drawer and not being able to choose a t-shirt to wear. "That went on for more than ten minutes, where I stood there virtually paralysed, not being able to decide what t-shirt to wear: not being able to overcome that indecision, whatever was causing it."
Sid’s lack of strong emotional supports becomes evident as he talks about his friends and family. He views his family as never having been able to provide emotional support to one another. Prior to his most recent return to university, Sid stayed with one of his brothers to recuperate. However, he felt that his brother had no understanding of his illness and he felt no closer to him at the end of his stay. There are no other individuals in his life whom he feels are really supportive, and no single activity in his life that stands on its own as providing him with support. The wife of the couple with whom he lives and a friend he met in day treatment a few years ago are his closest friends. He sees those relationships, however, as “moving and changing day to day” in response to his illness, and to others’ own priorities. Another factor contributing to his sense of aloneness is the absence of a suitable therapist. Sid had been in psychotherapy for two years, until his doctor decided to return to his medical practice in the summer of 1995. The search for a new therapist is emotionally upsetting for Sid and affects his academic performance.

**The Impact of Sid’s Illness on his University Education**

Depression affects Sid’s life in several ways. These include what Sid describes as “mechanical aspects” - problems in short-term memory, inability to concentrate and think clearly, problems with reading and studying effectively.

There are periods when I am unable to do any work at all. If I go through a bad week or two-- for any student it becomes difficult to catch-up-- for me, having difficulty reading and studying in the first place, it becomes impossible to catch-up. I start to become overwhelmed by the work and it starts to take the enjoyment out of learning.

Sometimes Sid’s symptoms prevent him from attending classes. He becomes so depleted in energy and feels so hopeless that he is unable to motivate himself to leave his room.
For me, every day is a challenge. every step is a challenge. just to get out of bed in
the morning, just to come into class, to take notes, to maintain concentration...
Without a strong sense of hope and consequently without at least a medium level of
motivation. I can’t see myself succeeding in life.

Sid’s illness also has broader effects. Although he came to university partly to have the
opportunity of interacting with other people. most of the time he “chooses not to” because of his
sense of stigma associated with the illness. He describes two aspects of stigma: “How I as an
individual perceive what other people perceive of me and how I perceive myself.” He maintains that
individuals with mental illness enter into “low risk social situations” because they are generally
stereotyped as dangerous and violent.

Whether it be on television, in the movies, in the newspapers or on the bus or subway
coming up here, they see the difficulties people with physical and mental handicaps
have and how they are mistreated (i.e., those with mental illness) by others. They
have learned long ago, before they came to university or in the early stages of their
illness, to take low risks. They’ve seen it long before their mental illness hit and are
more sensitive to seeing it now, but they’ve seen it their whole lives and probably
most of them have engaged in it themselves. so they don’t take the risks.

Sid’s interactions with other students are also impeded by his feelings of low self-worth.
“The illness affects my ability to socialize. It stops me right off the bat, before considering a
relationship. I don’t feel like I am a worthwhile person to get to know.” For Sid, his low self-esteem
means that “it doesn’t take much, if it’s a look from somebody, an off-hand comment, to perceive
myself as a failure.” For example, if he gives a wrong answer in class and the professor points out
the error. even though Sid understands his mistake, the experience can make him feel vulnerable and sensitive.

I feel I've made a fool of myself in front of the class. Intellectually I know these people couldn't care less, and yet it feels like an emotional blow, as if the professor had walked over and stood in front of me and called me an idiot.

He feels more vulnerable with a professor than with students because he views the professor as having control over his academic success and he wants to be seen as capable.

The size of the university is very imposing for Sid. The large number of students discourage his interacting with others. He also attributes his reduced social contact on campus to his being at least twenty years older than most of the students in his class. Not feeling comfortable with most people, he finds socializing with students who are much younger particularly difficult.

He said that he would have found the peer support group for students with mental illness beneficial in overcoming his loneliness, but due to his illness and schedule conflicts, he only attended sporadically.

I would have liked to attend. It's comforting to know that there are peers within the university community who really do understand. I feel like I am the only one. Even though I know intellectually I'm not, I still feel that way.

Supports on Campus

Sid finds the service for students with mental health needs on campus extremely helpful. The “expertise in knowledge of the university system” made it easier for him to be able to negotiate the system, through informing him about procedures such as financial and academic petitions. Even
more important was the encouragement he received not to drop out, without which, he believes, he would have withdrawn prematurely from university.

It was that kind of encouragement right through that kept me going because it was something positive. It would have been too easy for me to drop out and not be noticed and fall through the sieve.

Sid feels that the main support for his being at university comes from his weekly individual support sessions on campus. He sees the purpose of these sessions as integrating his emotional life with the university. He contrasts the supports he receives on campus from the therapy he receives in the community. "My therapist deals with emotional issues, trying to find the causes, the underlying relationships, and to do something positive about my emotional state." In his private therapy he does not mention university at all. Sid does not see the university support system as providing "extended therapy" but functioning as "a liaison, a protective barrier to ease university stresses or anything to do with university."

Although I may discuss issues with you that have to do with things outside the university, your primary concern is how that affects me in terms of my relationship with the university and my life here at the university.

Sid also avails himself of the instrumental supports on campus. He has found the letters (identifying the academic accommodations he requires) to his professors helpful in legitimizing his special needs. This support lends credibility to his situation and makes it easier for him to approach his professors. The letters "validate me as much as walking into their offices with a cast on my leg would validate me. It is my cast." Despite this validation, Sid feels guilty asking for something that is "out of the ordinary." He does not feel that he has the right to accommodations such as
examination deferrals, and sees these ‘special’ requests as imposing on other people’s time. While he understands that these requests will benefit him, they are also a constant reminder that he has a problem and is "not good enough." He feels especially guilty when he is already taking a reduced course load, and thinks that he should be able to manage his workload without any ‘special’ consideration.

It’s demeaning to have to ask for a deferral, special assistance, special time. People with all the wonderful facilities that your office, financial aid and student accounts have in place for people like myself, and all the wonderful benefits that I have received from those folks, nevertheless, there is always attached to everyone of those the feeling that it’s a gift, something special, that it’s because I am more needy, that I am less a person.

Sid wishes that he could work at his own pace and be treated as an individual instead of having to petition every time he requires an accommodation, such as a deferral. He thinks that there should be a ‘special’ category for students with disabilities who need to work at their own pace without a specific time frame in which to complete their courses.

It would be nice if the university would treat me not as another student who is trying to get a degree in order to compete for a job, but someone with a disability who needs more time to take courses, the way someone with a physical disability needs a ramp. I’m here to learn the same things, but not necessarily at the same pace as some people. If I go through a bad few weeks, unable to read and study, I can’t catch-up, and I feel overwhelmed. That structure is set up for students who do not have those kinds of problems.
Sid would like to see built in structures at the university where his on-going need for accommodations is viewed as a normal procedure rather than his having to petition at the very times when he least has the energy to do so.

When I have to apply for a course deferral, while I know it would be beneficial from an academic standpoint, it also stigmatizes me. I would like a structure in place where I felt it was well within my rights to request an extension...If I could have special status where the university didn’t see me as competing with all the other students.

**Managing the Illness**

Sid thinks that if he were managing his illness well, he would not have “this constant latent wish of wanting to die.” He would like to deal more effectively with his mood swings, and believes that he needs to have “greater control” of his “internal” environment in order not to be so sensitive to what goes on around him. He says: “if I get a look or some sort of reaction that I interpret as negative, it’s a blow to my self-esteem. With a very low gas tank, any kind of stress can be devastating.”

He compares his experiences with depression as qualitatively different from other students, whom he sees as “managing to get through day to day while coping with all the things that go wrong.”

They may get angry that they can’t get a coffee break in the afternoon; they may be tired, but they manage to function through the rest of the day. There are times in the afternoons or in the morning for that matter when I can’t do anything. I may be sitting in front of my computer and not be able to read a line. Whatever I read is out
of my head and as soon as I’ve gotten to the end of the line, I can’t do anything. My brain has stopped functioning and I can’t force it back to working. I need a break, whether it be lying down or something. I tend to think that the things that I feel are worse or I perceive them as worse, and I perceive myself as not having the skills to cope with them.

Because he gives his mental health higher priority than his education, Sid does not pressure himself to complete his courses quickly. While he thinks it would be “nice to graduate and go back to work,” ultimately he believes that this is not possible until he recovers sufficiently from his pervasive feeling of “hopelessness.”

The Meaning of Sid’s University Education

There are times when I feel like I am a university student with some psychological problems, and there are times when I feel like a depressed person who happens to be going to university. Very clearly, when my mood is good and my motivation is at a reasonable level, then I can see further into the future and university takes on more weight of a stepping stone towards something else. When things aren’t going well, I can’t see very far into the long-term. At those times, being here is part of the therapy because it provides structure, a bit of challenge and something to do.

University is not a stepping stone to a career at those points. It is part of just getting through each day.

Sid wavers between a vision of a possible self who will graduate and have a career and a sense that there is “not much hope of that ever happening.” The interviews, he said, confirmed for him his vacillation between attention to his illness and to his university education. “Each experience
changes and changes in weight at any one time,” depending upon how he is feeling and how he is managing his life. Finishing university has a low priority until his mental health problems are under control. He does not have a sense of urgency about completing his degree. He says that “there is no career without my mental health, regardless of how many letters are beside my name. If I can’t function on a consistent level, there is no career.” He hopes that if he can go to university, while at the same time working on his mental health problems, that “the two will meet” and that he will be able to move on with his life. “I won’t have felt like I lost five or ten years of my life because something is going on.”

For Sid, the meaning of his university education is a difficult one for him to grasp because it changes all the time. When he returned to university as a mature student in 1990, his intention was to study and get a job in his field of interest, computer science. Since his first breakdown in 1991, which resulted in a year and a half long interruption in his studies, he has placed more emphasis on learning for its own sake than on achieving good grades. He is much more interested in the “quality” of his education and attributes his shift in emphasis to his illness. In his low periods, he has difficulty even seeing himself finishing university.

It’s much more difficult to see getting a degree and someone hiring me. Because I don’t see those things as almost very realistic, I’m not worried about them. In a sense I have been forced to lower my target.

Most of the time Sid has difficulty envisioning long-term goals. “When I am sitting in class and taking notes, I’m not thinking I’ll need this for my career.” In the short-term, the meaning of his university education is that it keeps him in touch with a social and intellectual milieu and gives him “real world things to do.”
On a more day to day scale of things, coming here is just part of the therapy. It would be easy for me to isolate myself and just sit in my room or in front of my computer at home and do nothing. So university gives me structure in just having to come to classes, work that has to be done by a certain time, as well as getting me out of my room and into the real world and making me feel normal because being a student is something normal, when most of the time I do not feel normal.

Post Script

Shortly after our third interview, in the latter part of the fall semester of 1995, Sid decided to withdraw from university. Another severe episode of depression had interfered with his ability to attend classes on a regular basis and concentrate on his studies. Currently he perceives himself as a "depressed person who is attending university." He thinks it would be best for him to return when he is able to be "a university student who happens to be depressed."
CHAPTER 5

RESULTS AND DISCUSSION

In this chapter, I intend to illustrate how the coding process described in chapter three became further refined to formulate a conceptual model of the meaning of education for students with psychiatric disabilities. I shall briefly describe the core category that emerged, promising to return to it and integrate it with all that will be talked about before.

It became evident early on in the analysis of the data that the trajectories of the students' university experience and illness experience were intimately linked. For example, the history of their illness (e.g., time of diagnosis, symptomatology, degree of involvement with the mental health system, hospitalizations) affected the history of their university studies (e.g., frequency and duration of interruptions, status as a part time student). The demands of university (e.g., time frames for completion of assignments, examinations, large and small classroom experiences) sometimes exacerbated symptoms of the illness (e.g., anxiety, fear or paranoia). How the students managed their illnesses (e.g., knowing and accepting their strengths and limitations, using effective coping strategies) and having support systems in place both on and off campus affected how they managed their university studies (e.g., taking a reduced course load, self-disclosing and availing themselves of academic accommodations and other support services). As well, the stigma of a mental illness affected the students' identity and how they functioned in the student role. See Table 3 for an outline of how the university experience and the illness experience were interrelated.

The core category that emerged - 'shifts and variations: integrating mental illness and education' - reflects the intimate and fluid association between the university experience and the
Table 3

Interrelationship Between University Experience and Illness Experience

<table>
<thead>
<tr>
<th>University Experience</th>
<th>Illness Experience</th>
</tr>
</thead>
<tbody>
<tr>
<td>history (frequency/duration of interruptions)</td>
<td>history (time of diagnosis, hospitalizations)</td>
</tr>
<tr>
<td>shifts in meaning of education (vocation/avocation)</td>
<td>shifts in meaning of illness (inconvenience/disability)</td>
</tr>
<tr>
<td>supports (academic/social/emotional)</td>
<td>supports (family/friends/mental health workers)</td>
</tr>
<tr>
<td>shifts in meaning of illness (inconvenience/disability)</td>
<td>stigma (in broader community/internalized)</td>
</tr>
<tr>
<td>identity issues</td>
<td>effect of learning on illness:</td>
</tr>
<tr>
<td>self-disclosure</td>
<td>symptomatically - heightened anxiety, depression, paranoia</td>
</tr>
<tr>
<td>self-acceptance</td>
<td>socially - withdrawn</td>
</tr>
<tr>
<td>self-understanding</td>
<td>emotionally - lowered self-esteem</td>
</tr>
<tr>
<td>acceptance by others</td>
<td>identity issues</td>
</tr>
<tr>
<td>understanding by others</td>
<td>self-disclosure</td>
</tr>
<tr>
<td>effective coping strategies to manage</td>
<td>acceptance by others</td>
</tr>
<tr>
<td>advice to other students</td>
<td>self-understanding</td>
</tr>
<tr>
<td>university providing hope/against all odds</td>
<td>understanding by others</td>
</tr>
<tr>
<td>illness as a motivator to persist/against all odds</td>
<td>effective coping strategies to manage</td>
</tr>
</tbody>
</table>
illness experience. More specifically, the meaning of the students’ education and their integration of that meaning with the meaning of the illness experience depended on several factors: (a) the unpredictability of the way in which the illness manifested itself over time. (b) the students’ shifts in identity in relation to their illness. (c) the students’ methods of coping with their illness both at university and in their daily lives, and (d) the students’ access to and use of effective support systems both on campus and in the community. The relationships among these various factors will be discussed more fully throughout this chapter. See Figure 1 for a diagram of the conceptual model.

Two main categories emerged - 'the university experience: education/recovery continuum' and 'the illness experience: identity/coping continuum'. Refer to Appendices ‘D’ and ‘E’ respectively for a description of the coding process that resulted in the development of each of the main categories, their sub-categories, and some of their properties. The method of approach to the material in these appendices will be to focus on the more prominent categories and sub-categories that were mentioned by the participants.

In terms of this particular study, the university experience and the illness experience were not mutually exclusive concepts. Although, for the sake of clarity, I shall talk about the university experience and the illness experience separately, it will become evident to the reader just how difficult it is to discuss these two main categories in isolation, when in fact they are so closely connected.

Main Category # 1: University Experience: education/recovery continuum

Meaning of Participants’ University Education

The participants’ goals and reasons for attending university were similar in many respects
FIGURE 1

CONCEPTUAL MODEL

SHIFTS AND VARIATIONS:
Integrating Mental Illness and Education

UNIVERSITY EXPERIENCE:
Education/Recovery Continuum

Meaning of Education
normalization
structure
hope

Barriers to Learning
technical (institutional)
medical (physiological)
social (external/internal)
educational (policies, practices
and procedures)

Supports to Learning
academic
social/emotional
inner resources

ILLNESS EXPERIENCE:
Identity/Coping Continuum

Manifestations of Illness
affective
cognitive
behavioural
medical

Management of Illness
identity over time
performance of daily life activities

Support Systems
family
friends
therapists
to the motives and sentiments found in the student body at large. They all identified the importance of acquiring knowledge, having an opportunity to interact socially, to improve their quality of life, to explore their identity and in many instances meet family expectations. Doug and Sid commented on the critical thinking skills that university education provided. Bob, Mark, Doug and Anne anticipated a good job and career resulting from their education. Doug, Bob and Mark saw attending university as an opportunity to develop greater independence from their families of origin. Several participants described an increase in self-confidence. Anne because of the positive feedback she received from her professors. Mark in being able to succeed academically and socially, in spite of his schizophrenia, and Mary in being the only one in her family of origin who had pursued higher education.

**Education/Recovery Continuum**

The meaning of the participants' education did differ markedly from the general student body in that it was greatly influenced by the illness itself and by fluctuations in the symptoms. Though the sample size was small, the findings of this study indicate a division of the participants into three groupings along a continuum - those students who, at the time of this study, saw university as a means to an end; those students for whom a university education was an end in itself; and those students who occupied an intermediate position. These groupings directly reflect the illness experience.

All of the participants saw their education as part of the recovery process. How they perceived and utilized that process differed among them. Although Bob, Mark, and Anne anticipated that it would take them longer than the average student to complete their degrees, as it had for Doug, they still viewed their experience on campus as having a specific termination. For this group of
students, all of whom were under the age of 25. being at university was part of the recovery process and a move towards a larger goal. Bob, Mark and Anne all anticipated a career in the mental health field. Although Doug's goals were less focused, he still viewed his university education as providing a means to a good job and an eventual career path.

The four remaining participants, all of whom were over the age of 35, were less goal directed. Participants like Mary and Jeff, both of whom had experience in the mental health system dating back to the 1970s, and who refer to themselves as "psychiatric survivors," viewed their university experience more as an end in itself. For them, being at university was the recovery process. In addition, university symbolized a move away from the label of "psychiatric survivor" and was their primary goal. They had no long-term plans for themselves, at the present time, beyond their studies. Coming to university was "a goal in itself" for Mary. Although she hopes to earn a masters degree one day, she said that she takes each day as it comes. "It will take me as long as it takes me." Jeff remarked. "I am not goal oriented. I am not here to get a degree or a job. I just enjoy learning. I am here mostly for the knowledge and contact with others." Being at university, therefore, presented a viable and more rewarding option than their participation in community based psychiatric programs. For Anne, too, being a student formed a strong part of her identity. However, unlike Mary and Jeff, who did not necessarily foresee themselves in the workforce. Anne expressed a definite goal to become a professional in the mental health field.

Sid and Omer formed a third grouping somewhere in between these two groupings, perhaps because their situations were more precarious at the time of the study. Both of them withdrew from university shortly after their interviews were completed. Though Sid came to university with the hope of acquiring further expertise in computers, his mental health issues were sufficiently in the
foreground that getting better was his main priority. He was realistic in recognizing that “there won’t be any career if I don’t have my mental health.” Since the development of his illness, he placed greater emphasis on the quality of his education than the competitive aspect of it and, like Jeff, he enjoyed learning for learning’s sake.

Omer had a difficult time setting realistic goals for himself. He held a very different perception of his circumstances from those of the other participants. He viewed his education as a “mystical quest” with an “internal purpose” that he hoped would provide him with “inner discipline” and cure him of his symptoms. On his return to university after his first unsuccessful attempt at a degree in the 1970s, he remained unable to make any academic progress. However, it was difficult for him to withdraw from his courses. His anxiety disorder, and his obsessive compulsive disorder that he described as “chaining him to activities,” in fact, chained him to continuing his studies unsuccessfully. Only by reading and re-reading his transcripts did I come to appreciate just how much he was struggling academically. As a result of our four interviews, once the research was completed, I raised the possibility that he seek an alternative program where he might gain greater mastery over his environment.

The participants’ responses concerning the meaning of their university education contained three common themes or sub-categories (a) the normalization of their lives, (b) the provision of structure and routine, and (c) a sense of hope.

Normalization

University attendance offers people with mental illnesses many rewards: For Jeff and Mary, their role as students helped them to step out of their role as “psychiatric survivors.” For Doug, the experience provided him with an “alternative way of being, other than depressed all the time.”
Although Sid did not emphasize the importance of normalcy to the same extent as the others, he did indicate that “being a student is something normal” and that the student role resulted in his thinking about himself as “being normal.” The status of university student enrolment is a highly valued one in our society, especially for persons with mental illness (Hoffmann & Mastrianni, 1989; Unger, 1993). Even if the participants did not interact on a personal level with members of the general student population, being at university helped make them feel less isolated and more connected to the mainstream.

Structure in Daily Life

All of the participants mentioned the importance of the structure and routine that university provided, giving them something to look forward to and establishing a purpose to their lives. School helped motivate them to get up each day and leave their rooms. For Bob, who saw being a student as “part of the recovery process,” his self-confidence had increased because of the demands of university:

You have limitations, but you still can achieve your long-term goal...If you’re busy doing work, you are not always reminded about aspects of your illness and that you have an illness.

Being kept busy helped Anne keep her mind on her studies; otherwise, she said that she would “sit and think too much and get depressed and feel down.” Sid remarked:

It would be very easy for me to isolate myself and just sit in my room or in front of the computer at home and do nothing. So university gives me structure in just having to come to classes, work that has to be done by a certain time.
Jeff described the structure provided as an “implicit” reason for his coming to university. Besides giving him freedom from his role as “psychiatric survivor.” coming to school was a “distraction.” and gave him “somewhere to go, like the library.” The importance of engaging in productive activity as a means of developing feelings of dignity, self-respect and hope, as these participants described, has been reported in the literature on people with mental illness (Arns & Linney, 1993; Lefley, 1994; Woodside, Landeen, Kirkpatrick, Byrne, Bernardo, & Pawlick, 1994).

Hope

The role of hope as an important ingredient in the recovery process for persons with psychiatric disabilities has been corroborated by professionals as well as consumers of the mental health system (Anthony, 1993, Anthony et al. 1990; Deegan, 1988; Leete, 1988; Kirkpatrick et al. 1995). The participants in this study made it plain that hope was an important, even powerful, factor in their role as students. Mary commented:

If I didn’t have school, I don’t know what I would do. It keeps me going. It’s something to look forward to. I may not be alive today if I didn’t have something to look forward to.

Sid saw his motivation level as being linked to his sense of hope. “One complements the other. Without at least a medium level of motivation, I can’t see myself succeeding in life.”

The recovery process for persons with mental illness often means a willingness to try and fail and try again (Deegan, 1993). The participants’ experience of hope was not a static condition. Hope is best understood when contrasted with its opposite - hopelessness. The students reported having fears that their hope of completing their studies might be dashed. Mark commented:
I feel a bit discouraged. I see my sister age 21 graduating this year. I am 24. I've been here three years already. It's going to take me at least another year.

Students conveyed a variety of other fears: not being able to find a job, having to be hospitalized again, being misjudged, being rejected socially. Their fears, intermingled with their sense of hope, prompted me to produce a lower level category called "against all odds." for in spite of their fears and the unpredictability of their illnesses, they persisted in their endeavours. This category will be described more fully under discussion of the core category.

**Barriers to Learning**

The participants described barriers to learning as technical (structural), medical (physiological) and social (internal and external). Educational policies, practices and procedures, while intended to assist the students, sometimes served as obstacles to their learning.

**Technical Barriers**

While many of the technical barriers described by the participants (e.g., institutional size, not getting into courses of choice, lack of availability of professors, having to meet deadlines) are experienced by many members of the student body, these challenges created an added burden for the participants because of their illnesses. Until he was linked up with the advocate’s office, Omer said that the physical size was so daunting that he felt overwhelmed, not knowing where to go for help. Doug described the university as “huge and impersonal.” particularly for someone with a mental illness, “who is already feeling a little bit isolated and socially insecure.”

**Medical Barriers**

Because of their illness, the participants viewed their stresses at university as qualitatively different from those of the general student body. “The illness itself is a barrier.” stated Bob, and in
many respects made it harder for all of the participants to study effectively. They had difficulties with short-term memory, anxiety, concentration and motivation. Fluctuations in their symptoms often meant interruptions in their studies. Sometimes these interruptions were temporary; with accommodations, they were able to get “back on track.” Some of the interruptions, however, were of a longer duration and necessitated a withdrawal from the academic term or year. As a result of these fluctuations, they saw themselves as needing more continuous accommodations than an average student did.

Educational Barriers: Policies, Practices and Procedures

Although my thesis explored the meaning of education for eight individual students with mental illness, the focus cannot be on them alone. It is important to understand how persons with disabilities and differences are responded to by faculty, staff and administration. Within the university, Doug saw his intellect as his measure of worth: “Sometimes I think I don’t deserve to be in such an academically enriching environment and I think that I won’t be able to make it.” He was afraid to ask for supports, not believing that he truly deserved them. Omer expressed the same sentiments. “You feel like you are hurting your own self-esteem by getting something privileged.” There was never any sense that the participants wanted to take advantage of the accommodations that were due them. In fact, except for Mary and Jeff, they were reluctant to make use of many of the services. Doug commented:

I don’t want any advantage over any other student. Sometimes when I do get extensions, I feel I don’t deserve them. You have to look at it as a levelling of the playing field because I am working with a disadvantage and this is the best way to accommodate for the problems that I have...When a professor understands, it goes
a long way to making the experience more productive. It’s nice to know that I
don’t have to feel like a criminal, that it is something I have to impose on them
because the university has mandated it.

Just as the findings describe how the students integrated their university experience and the
illness experience into their lives on a personal level, it is equally important to consider how
educational policies, practices and procedures influence this integration process at an institutional
level. Bogdan and Biklen (1993) proposed that the inherent structure of service systems for people
with disabilities often works to promote handicapism. “A cornerstone to the handicapism of
professional systems is that services to the disabled people are considered a gift or a privilege rather
than a right” (p. 74). Sid echoed these words when he commented at length:

I do know about extensions. It’s more an understanding from the professors. The
extension I had from the professor was useful. I never had that before. But it was
very difficult for me to get in and see the professor for one thing...That was one
difficulty...Even if he could have given me the time, I had to deal with my own
feeling of guilt, asking for something that was totally out of the ordinary and
imposing on his time. If there was some other structure in place...if I could have had
special status where the university didn’t see me as competing with all the other
students...If there was a category where I could be classified as a special student and
it was an accepted part of the university, where as a ‘special student’ I could take
courses and where I could take tests when I was ready for them, so that there was no
requirement for me in terms of the financial end of things...where if classified as a
special student, when I felt I could only deal with one half course over an entire year.
if that's all I took, as far as the university is concerned, that is fine, and if I could take more and did take more that was fine too...If I felt by having some status, unnamed, that I could call myself a `special student’, that was accepted within the university community, then I wouldn’t feel bad going to the professor for assistance...There was the feeling that I didn’t have the right, that I was asking for more than I was paying for to have that time with the professor, because all the other students had their three hours a week with the professor in the classroom. They could go and see him for a question or two. What I would have needed was a little more time with the professor, which is not to say I wouldn’t come to class, but there were times when I couldn’t come to class and even when I could come to class, sometimes I needed more time and not just to ask one question, because sometimes I wasn’t able to do the reading...There has to be a way I can rationalize it and not feel so guilty about it.

Social Barriers: External and Internal

The social barriers reported by the students related directly to the effects of stigma of mental illness and included two levels - external barriers, in terms of how they felt others responded to them (e.g., lack of understanding and acceptance of mental illness by members of the university community, family, relatives, friends, employers and the community at large), and internal barriers, in terms of how they felt about themselves (e.g., self-awareness of stigma affecting their ability to self-disclose, ask for help and risk themselves in social situations). While the role of instructors merits specific attention here, the role of family and community is more appropriately discussed under the core category.
External Social Barriers:

i. Staff Attitudes: Role of Instructors

Although the students reported that an understanding professor, teaching assistant or an academic advisor could be an important support, staff attitudes also functioned as obstacles when these supports were absent. Doug expressed this idea well when he said: "There are just some professors who don’t care and you are just a problem to them and that can be very discouraging."...

"If a PhD doesn’t get it, it must be me." The students readily felt shunned by a professor or staff person who spoke curtly to them or who was not perceived as compassionate or accessible.

All of the participants felt that it was important for their instructors to have a better understanding of mental illness, although there was no consensus on how to achieve this. Some suggestions were: faculty and staff participation in a workshop sensitizing them to the issues of various disability groups, distribution of pamphlets on various mental illnesses and education of faculty on a case by case basis, around a particular student in their class.

Internal Social Barriers

Socially, the students described feeling more vulnerable, less likely to let people really get to know them. They all found it difficult to convey their concerns, not only to people whom they did not know well such as their instructors, but to anyone who was not living with a mental illness. The students felt that unless a person had experienced mental illness first hand, he or she could never truly understand what their lives were like for them.

i. Self-disclosure:

One of the consequences of persistent stigma is the need for secrecy (Murphy & Irwin, 1992). The students’ comfort in discussing their educational concerns with their instructors
depended on, among other factors, their internalization of the stigma associated with their condition. In general, most of the participants found it demeaning to ask for help and often felt they did not deserve it. Omer experienced great difficulty in conveying his problems to his instructors. "If you have a self-image problem and talk about your problems, you feel other people will think less of you." Mark noted that:

I've always been afraid to go up to a teacher and say I walked out of class yesterday because I couldn't handle myself and I had an anxiety attack. By expressing it, it makes me feel bad and it decreases my self-confidence. I just would never do that. I'm afraid of the consequences, what they think. It's difficult to open up. You are afraid of people's reactions, that's the bottom line.

Although Mark let his instructors know when he was experiencing academic difficulties, he was hesitant to disclose anything about his illness to anyone unless he felt that he knew the person well and could trust him or her. Whether other people's reactions were experienced or imagined, they appeared to act as a sufficient deterrent to the participants readily identifying their illnesses to others.

The participants' self-esteem and other social and emotional issues were linked to how they viewed their functioning as university students, especially in the area of self-disclosure. Disclosure is particularly problematic in an academic setting where, as Doug mentioned, a student's worth tends to be measured by his or her intellectual ability. Self-disclosure was seen as a double edged sword. The students did not want to disclose for fear of being misjudged, yet they needed to disclose in order to receive the necessary services. Doug conveyed this ambivalence when he said: "It's a touchy subject because you want to keep your illness to yourself, yet how do you educate people at the university if you do?" On the occasions when he did disclose to a faculty member or a petitions
officer, he questioned whether he did the right thing. Mary, too, expressed doubts about her decision to disclose her illness to some of her professors.

Although the participants felt comfortable describing their functional limitations to their instructors, none of them felt confident in disclosing their diagnoses. Mark, for example, believed that it was important to inform his professors when he experienced difficulties. “I think that makes them more sympathetic and they can help you a lot more than if you don’t say anything.” However, he would never say that he has schizophrenia.

Anne was the only participant who expressed concerns about disclosure at the graduate level. As she contemplated pursuing a doctoral degree, she considered what and how much information she would need to disclose to her supervisor. She is concerned that a poor opinion on the part of a supervisor could negatively influence chances to pursue graduate studies. “Do I not say anything until I have a problem, or do I warn them that I have a problem, and if so, will that affect the way I am treated?” This whole area of educational concerns for graduate students with mental illness has yet to be addressed in the literature.

There was full consensus among the participants that there is very little understanding about mental illness in society. The students felt most comfortable disclosing to close family members, friends and a select few, trusted instructors and staff on campus. Bob was careful to whom he disclosed: “Besides my immediate family, a lot of people don’t know because people are going to stigmatize me. The more people who know, the more you are going to experience trouble.”

Mark and Bob felt it prudent to “pass” as no different from other employees at their regular part-time jobs. They both feared losing their positions if their supervisors knew about their illness: yet both felt comfortable in sending letters to their professors identifying their special learning needs.
without disclosing their diagnoses. Omer, on the other hand, had difficulty disclosing his difficulties to his family, as well as to people in his support system. It is not uncommon for individuals who have an invisible disability to try and “pass” as the same as other people (Goffman, 1959; Murphy & Irwin, 1992; Todoroff & Lewis, 1992).

In summary, labelling and stigmatization played a key role in the social isolation and difficulties with self-disclosure that many of these students described. In response to their sense of stigma, the students internalized their shame and embarrassment at their illness, comparing themselves unfavourably to non disabled students.

technology: Social Interactions:

The opportunity to interact socially was both a source of support as well as an area fraught with its own difficulties. Although one of Sid’s reasons for coming to university was in order to socialize with the other students, he chose not to. He attributed his actions to his age, his illness, and his self-esteem:

I don’t have a lot of contact with the other students because I am 20 years older than most of them... My illness affects my social interaction...I don’t think I am a worthwhile person to know.

He felt vulnerable and sensitive to his external world and described himself as not having strong defence mechanisms to handle off-handed comments or a look he perceived as unfriendly.

The slightest thing can be devastating and under those circumstances it is very difficult... I have a difficult enough time just dealing with taking a couple of classes, sort of trying to keep myself alive, not getting suicidal. To socialize, therefore, is a low priority.
Mary. Jeff and Omer. the other older students in this study. also expressed similar concerns about interacting with a younger group of students.

Jeff candidly admitted that he had difficulty establishing social relationships at university. “It’s been kind of rough as far as the social aspect has gone.” Doug said he found it very difficult to approach people when he felt depressed. “Depression makes it harder to socialize with people when you question your abilities.” Similarly. Mark avoided socializing with peers on campus when he felt agitated. Since the development of his illness. Bob perceived himself as more sensitive to social situations and to how he thinks people relate to him. Although more attentive to his social milieu. he also felt that this hypersensitivity sometimes worked against him because he sometimes misread social situations. Omer thought that he spent too much time by himself. thus becoming more depressed. Though he found being with others socially uplifting. he felt that he had too many personal and academic problems that interfered with his ability to socialize. Mary took advantage of the Mature Students’ Association on campus. but did not feel entirely comfortable there. She felt that because these students did not know what she was experiencing. she had to “watch” what she said: “You don’t want to look like you’ve got problems.”

**Supports to Learning**

Supports of both an academic and social/emotional nature played a vital role in helping the students to overcome the geographic size of the university. negotiate the bureaucracy and manage their studies. The students’ inner resources (e.g., assume responsibility for their learning. access supports available to them. have effective coping strategies to manage the demands of university) were also an important part of how they functioned in the student role.
Academic Supports

The students identified academic accommodations - extra time in which to write tests and examinations and separate rooms in which to write them if necessary, petitioning, academic advising, learning skills workshops, extensions on assignments, letters to professors identifying their learning needs - as very helpful. Most of these supports have been documented in the literature (e.g., Frado, 1993; Unger, 1992; Weiner & Wiener, 1996). Letters to professors were consistently cited as extremely beneficial in opening the door to dialogue and as helping the students feel that their needs were legitimized. For Mark, they were an "ice-breaker." For Sid, they were a validation of his needs. For Anne, they made her concerns more bona fide.

Social/Emotional Supports

In her study of the social dimensions of relationships, Josselson (1992) included "holding" as one of the most basic needs human beings have to grow emotionally. She referred to different ways of holding. A person can be held physically, as in infancy by a mother, or later be held emotionally, "by institutions and ideas" (p. 31). It is the latter kind of holding of which the participants spoke.

In a study of 132 non-traditional students, Terenzini et al (1993) found encouragement to be a vital component of students' academic perseverance. Whether it was over the telephone or in person, the participants talked about the emotional support they received from academic advisors, instructors, compassionate receptionists and staff. An understanding professor had a profound and positive impact on how they felt about their studies. Omer remarked: "When you get into a class with a warm and friendly professor, it tends to help you feel better about yourself, to feel encouraged and not feel so depressed." Doug echoed these words, stating that it made the experience "that
much more worthwhile.” Tinto (1982, 1993) found substantial evidence to show that availability of professors through less formal interactions outside the classroom were an important part of the students decision to pursue their education.

i. Support Services for Students with Mental Illnesses:

All of the participants felt that it was important to have an advocate on campus to work on their behalf and help them negotiate the bureaucracy. Bob stated:

It helps to have a person at the university who has contact with people throughout the university such as professors and people in advising who can help. If the student has to leave school, [this person] can assist the student with petitions, writing letters to professors, and offer counselling.

He saw the university advocacy program for students with mental illness as helping to empower him by linking him to resources and facilities within the system. The university advocate helped Sid and Omer learn about the procedures in place for students with mental illness at the university. Omer said that by having someone to go to on campus, he no longer saw the university as a "formidable place." Sid felt that without being informed about and assisted with petitions, he would have withdrawn from his studies. The counselling he received around these procedures reinforced for him a sense that he deserved the accommodations. He expressed that “the encouragement right from the start” had kept him motivated. “It would have been too easy for me to drop out and not be noticed.”

The emotional support, he believed, helped him much more than he would have been able to accomplish on his own.

ii. Peer Support:

Although there is strong emphasis on academic performance at university, what occurs at the
peer level in terms of the students' social and emotional growth is also an important part of the learning experience (Kuh. 1993: Pascarella & Terenzini, 1991). Whether the participants chose to interact with members of the general student population on a more personal level or primarily with members of the peer support group, they described the social and emotional support from their peers as important to them. How they engaged in social contact depended in part upon their age, how they were feeling at a particular time, how they viewed themselves and how they felt they were perceived by others.

Doug and Mark alluded to improvements in self-confidence, and Mary to a sense of accomplishment, as a result of their interpersonal relations on campus. Mary reported the strong encouragement she received from a fellow student whom she met in one of her classes, as well as the emotional support she received from her husband who is also a university student. Mark referred to the emotional backing he received from his girlfriend, a fellow student on the same campus. Doug said that he gained self-confidence by expanding his social world and interacting with students from different walks of life.

iii. Peer Support Group:

Peer support groups are seen as a means of identifying common concerns for specific student sub-groups (e.g., Horle & O’Donohue, 1993; Rifenbary, 1995; Weiner & Wiener, 1996). One of the supports provided by the service for students with mental illness is a weekly peer support group. Facilitated by me, it runs during the academic year from September until April. The purpose of the group is three-fold: (a) to enable students with mental illness to meet other students in a similar situation and to feel less socially isolated, (b) to familiarize the students with resources on campus (e.g., library, career centre, athletic complex) through visits to these facilities, including key
individuals who can advocate on their behalf (e.g., ombudsperson at registrar's office, learning skills specialist, academic advisors). and (c) to have the opportunity to discuss their concerns and problem-solve with peers in a similar situation. The students who attend the group range in age from their early 20s to late 40s. Within the confines of the group, age was not reported as a barrier to how the participants related to one another.

Doug attended the peer support group for a limited time period, early in his studies. Among the students in this study, he was exceptional in his immersion in the out-of-classroom experiences - social gatherings on campus, pub meetings with his professors and classmates, participation in both on and off campus activities with friends he made at the university. Similarly, Anne attended the group on a limited basis, and only during the year when she was feeling depressed. All along she maintained her friendships off campus and, as she grew stronger emotionally, she did not see the group as her mainstay. Neither Doug nor Anne were as deeply involved in the mental health system as the other participants and were able to interact with non disabled peers.

Although some participants attended the peer support group on campus on a limited basis, others viewed it as their main form of social contact. Omer’s primary social relationships were formed within the group. He did not participate in any other social activities on campus and deeply missed two former group participants when they left campus. Mary also identified strongly with the peer support group, saying that it helped her in “knowing what students with similar problems are going through and how they deal with them, and for them to know how I deal with mine.” Although she visited an association where mature students convene, it was more on an ad hoc basis. It was with the students in the support group that she felt most comfortable. Jeff attended the group
when he was taking a course at the larger campus. He occasionally attended when he came to use the library.

Bob moved comfortably between both worlds. He socialized with peers in the support group as well as with other friends on campus. He was also on the executive of a student club on campus. Although Bob did not see the group as providing him with his main social support, it allowed him "to learn about how other students are coping." He enjoyed hearing about other people's experiences. He also found it a way to network and learn more about the resources on campus. Omer felt he could be more himself in the group. Even though Sid only attended sporadically, he found it comforting to know that there were peers who really understood him. The only student who did not attend the group was Mark. He had a strong social network off campus, and a serious and long-term relationship with a girlfriend. He was also working part-time and said that he did not have the time.

iv. Inner Resources

Coping with the university experience came not only from the academic and social/emotional supports described, but also from the participants' own abilities to employ effective strategies to monitor the demands of campus life (e.g., negotiating the system, handling the copious amounts of work and meeting deadlines). These coping mechanisms included strategies such as choosing appropriate courses, avoiding early morning classes, taking a reduced course load, making use of accommodations, participating in a peer support group and communicating their concerns to others, while simultaneously managing their illnesses. Refer to Table 4 listing the reported strategies the students employed to manage their stressors at school.
Table 4

Strategies to Manage the University Experience

- access resources on campus (e.g., university advocacy service, learning skills workshops, individual counselling, financial aid, academic advising, psychiatric consultation as needed, peer support group)
- make use of academic accommodations as needed (e.g., extensions on assignments, proctoring of examinations, petitioning process)
- plan course selection well in advance
- take a reduced course load
- develop short-term goals
- send joint letter (with university advocate) to instructors identifying 'special needs' status
- communicate with faculty when experiencing difficulties
- manage time effectively - take workshops, use a day planner, divide tasks into manageable bits
- try and avoid early morning classes
- take anti-anxiety pill before class or examinations as needed
- sit with people you know in lectures
- tape lectures
- leave class if necessary when experiencing paranoia, extreme anxiety
- comply with medications - get exercise
- engage in positive self-talk - have good mental attitude
- participate in a peer support group
Main Category # 2: The Illness Experience: identity/coping continuum

The Trajectory of Mental Illness: A framework for analysis

A trajectory framework as a means of studying the management of chronic illnesses such as cancer, diabetes and cardiac ailments was developed by Strauss and his associates. (e.g., Corbin & Strauss, 1988, 1991; Fagerhaugh & Strauss, 1977; Glaser & Strauss, 1968). “The trajectory framework is a conceptual model built around the idea that chronic conditions have a course that varies and changes over time” (Corbin & Strauss, 1991, p. 156). I discovered this model in the nursing literature only during the final stages of analysis of the data. It seemed to capture the findings of my study. The trajectory model considers the course of a chronic illness and also action that is taken around the illness. The attempts to shape it, for example, through medication, diet, reduced activity level, exercise and positive thinking are an essential part of the trajectory framework. The model incorporates three main components: (a) the manifestation of illness, (b) the person’s identity over time in relation to the illness, and (c) the performance of daily activities to help manage the illness (Corbin & Strauss, 1991). These three components of the model will be discussed in terms of my study. Because the students’ identity in relation to their illness was so closely tied to how they coped with daily activities, these two categories will be incorporated under the heading ‘Management of the Illness’, as reflected in Figure 1 on page 119.

Manifestations of the Illness

There are various effects of the mental illness (affective, cognitive, behavioural, and medical) that need to be recognized, irrespective of management techniques utilized to handle the symptoms. (See Appendix ‘E’.) The students described feeling anxious, depressed or upset for extended periods of time. Sid referred to the “mechanical” components of his depression such as problems
with short-term memory, concentration and decision making skills. Mark would sometimes hear voices. Omer described a "lack of flexibility" in his activities due to his obsessive compulsive disorder. Doug's repetitive actions made it difficult for him to leave the house and get to classes on time because he "keeps checking things." Bob had trouble "motivating" himself because of his illness. In addition, negative side effects of medication can sometimes play a major role in causing additional symptoms. They were most visible with Jeff, who developed dyskinesia. The negative side effects of psychotropic medications (medications that alter mental functioning) range from uncomfortable to life threatening (Baldasserini. 1991: Krogh. 1994) and need to be seriously considered as an area of study worthy of further investigation.

Management of the Illness

Identity Over Time

A critical element of the students' illness management was the way in which they identified themselves with their illness. This identification process changed over time. At the time of this study, Omer and Sid seemed least able to separate the illness from their personal identities. Sid identified completely with his illness. "I see myself as a depressed person and that perception affects everything I do... It is the primary aspect of my personality." Similarly, Omer saw his illness as the "biggest" part of himself. He commented that he could not imagine a future in which he was going to be "completely right."

Anne, on the other hand, was coming to terms with managing and accepting her illness as part of her, but without identifying with it completely:

I got so driven with my school. It identified me. Also I couldn't manage the illness.

It was running me. What I am trying to manage now is to realize that I do have
depression but that it doesn’t totally define who I am as a person. It doesn’t mean that I am a sick victim who doesn’t have control over my life.

Over time, Jeff moved from the position of seeing himself as a schizophrenic to a person with schizophrenia. This shift in self-perception, he believed, enabled him to move from being mostly preoccupied with how the illness and his medications were affecting him, to pursuing other interests and his taking his medications more regularly. Mark, as well, did not view his illness as his core self, stating: “This is my illness and this is me. I still have a life and I am not paralysed by it.” Bob treated his illness as he thought someone with a physical illness would. “I have this illness. I take meds for it. I get on with it.”

i. Stigma:

Although no participants talked specifically about losing friends since the development of their illness, some indicated that their social world had changed. Even Mark, who had been with the same friends since grade seven, did not see them as often as when he was first diagnosed. Although he was unable to state with certainty why the situation had altered, he thought that it might be related to his mental illness. “I’m not so sure if it’s because we just grew apart or that they don’t understand and live in the world of stigma of the mentally ill as violent and crazy.”

Sid spoke eloquently about how he and other students with mental illness avoid relationships for fear of being shunned:

...I would certainly not discuss my problem with a lot of people because I have seen an attitude of how people with physical and mental handicaps have been and are treated by others...They learned long ago, before they came to university, or in the early stages of their illness, to only go with very low risk situations...Before my
depression hit I was insensitive to mental illness. I had some very incorrect notions in my head about what mental illness was, because I blinded myself...I think many people have a fear of mental illness. many normal people, and so they do not want to know too much about it because there is a fear that knowing too much about it may lead to them experiencing it.

Doug saw people regarding mental illness as a failing, "a defect in one's personality. that someone cannot tough it out." He added: "When you don`t function. you start to question your abilities." Omer observed: "People think you are doing something on purpose and that it is a character flaw." Anne questioned the legitimacy of her illness. "If it`s not biochemical. you think that you caused it yourself."

Wright (1983) maintained that the rigid definitions of what are perceived to be normal standards of behaviour by the non-disabled world are considered favourable. Persons who do not meet these standards are devalued, and in response to this social perception. devalue themselves. As Goffman (1963) noted, stigma negatively affects its bearers' self-esteem. Throughout the interviews, I often heard self-deprecating remarks from the participants. When a professor of Anne's made a comment that was “out of line.” she interpreted his words as “true.” Omer thought: “deep down I am a shallow person.” Sid did not feel that he was “a worthwhile person to know.” Doug chastised himself for his writing problems, saying: “I should be in kindergarten.”

Stigmatization can produce symptoms such as shame (Deegan, 1993; Retzinger, 1989; Shaw, 1991; Zola, 1993). Doug described feeling “embarrassed and ashamed” of his illness. He was aware that his rituals and repetitive behaviours were difficult for people to understand. “They think you are a little weird. They think you are less of a person because there is something wrong with you.”
Sid felt an “emotional blow” when he did not get the right answer in class. Mary felt that she would not be accepted or understood by other mature students if they knew that she had a problem. Omer was afraid of disappointing others and often told people what he thought they wanted to hear. Jeff said that his illness sometimes made him “scared to face other students.”

Thus, the role of stigma, which has been well documented in the literature on persons with psychiatric disabilities (e.g., Goffman, 1963; Link, Cullen, Frank, & Wozniak, 1990; Mansouri & Dowell, 1989; Wahl, 1987; Weinstein, 1982), was a critical factor in how the students incorporated their illness into their identity, how they managed their illness and how they functioned in the student role.

ii. Students’ Own Acceptance and Understanding of their Illnesses:

Although all of the participants appeared to have a good understanding of their illness, they were at different stages of acceptance. They reported that acceptance was harder to achieve than understanding, the latter being on a cognitive level and the former on an emotional level. Anne said that she understood her illness in an intellectual way, but believed she had difficulty accepting it on a personal level because “it is too painful to deal with.” Doug reported that, although his knowledge and understanding came from reading and from the medical establishment, he was still wrestling with acceptance. He refused to adopt the label ‘mentally ill’.

Self-acceptance is a recognized aspect of the recovery process for persons with psychiatric disabilities (Hatfield & Lefley, 1993). There are different stages of acceptance. Deegan (1988) described three stages of recovery: denial, despair/anguish and hope. Arrival at self-acceptance was not a linear process for the participants, but involved a process of trial and error, often while they were in the middle of their studies. Consequently, they sometimes were unable to take advantage
of the support systems in place. For example, Doug hesitated to appeal an initial rejected petition for deferred standing and only did so when he was close to graduating. Omer was reluctant to let people in his support systems both on and off campus know just how much he was struggling. Acceptance of his illness was inhibiting, since he equated acceptance with "giving up." He related his struggle to accept his illness to his difficulty managing it, to not finding the appropriate therapy and to low self-esteem.

I was hoping that with medication, though I know my illness will never go away, it would be reduced to a manageable level so that I can perhaps function, though not completely normally. Then I think that I can work to have a better acceptance of the illness than at the moment...You have to achieve a balance because if you don't accept it at all, you may try more than you can handle and sometimes refuse accommodations, while at the same time if you accept it, it can lead to you feeling kind of helpless and always needing support from somebody.

Mark, Anne, Sid, Bob, Mary and Jeff, on the other hand, knew when they were not managing and needed to reduce their course work. Sid was very clear in dealing with his mental health problems first and foremost. Bob said: If you accept the illness, you have to realize you have limitations academically and that you can only take a certain number of courses." Even though Mark compared himself to students who were younger than he was and further along in their studies, he felt that he accepted his illness and knew his limitations. Bob described acceptance and understanding in the following way:

You learn acceptance and understanding from other people, but you have to figure out the rest on your own. You have to think about your limitations, what you can and
cannot accomplish. You have to know when to stop and say this is too much for me.

You learn to set goals for yourself according to that.

Understanding and accepting their illnesses with its concomitant limitations was an important factor in its management. Understanding and acceptance involved more than coming to terms with the diagnosis. It also involved accepting the prognosis and its long-term implications. These findings have been reported in the literature for most people with mental illness (Gant, Goldstein, & Pinsky, 1989; Torrey, 1988).

Performance of Daily Life Activities

Having effective coping strategies is an important part of the recovery process and is vital to preventing relapse (Leete, 1989). All of the participants saw it as important to have some “control” over the illness, i.e., effective coping strategies to handle the fluctuations in their symptoms. Bob stated: “What I mean by control is that when it comes to a period of lowness or instability, I’ll know what to do and how to react and treat it.” He readily recognized when he had to go into the hospital. For Anne, control meant “knowing how to deal with stresses so that they don’t take you by surprise.” Managing their illness was a critical component in how they managed their university studies. As Sid commented: University has a low priority until my illness is under control.” It took Doug several years of struggling and having to drop courses before he came to the realization that he needed to have better coping strategies to manage his illness. He felt that he had a harder time than many students, not only because he did not have clearly defined goals for himself, but because of his illness and poor coping abilities. Having a good strategy in place for Doug meant that “you can go a long way in helping yourself versus letting the illness take over.”
When the illness figured more prominently and moved to the foreground, the participants’ university education had to be subordinated, which sometimes meant further reduction of course work. Requests for accommodations such as extensions, or even temporary withdrawal from their studies. Omer spoke of needing a better way to deal with his problems before he could continue his studies. Although he had hopes of earning a degree and finding employment in the computer field as well, his illness and his difficulty managing it were of serious concern to him. Reluctantly, he acknowledged that he needed to have his illness under control before being able to achieve at least a moderate level of success at the university. He withdrew to pursue a less academically demanding and more structured social/vocational program that he hopes will meet his present needs.

The students had to learn what they could handle in terms of course load and know what to do when the illness took over. They described management of the illness on two levels, a generalized level and a more concrete level. The former refers to the broader concept of balancing their education and their illness so that their lives had some stability. The latter refers to the more specific strategies they needed to have in place in order to manage their stress level. Strategies to manage the illness included: involvement with the mental health system for treatment, involvement with family and friends for understanding and support and more specifically, the use of individual techniques to cope with stress (e.g., relaxation, reduced activity level, positive self-talk). Refer to Table 5 for a list of strategies described by the participants as helpful in managing the illness. The importance of mental health consumers being able to manage their illness has also been described as key to their success by other researchers (e.g., Breir & Strauss, 1983; Leete, 1989). Managing includes having a positive attitude, being able to recognize symptoms and taking action to counteract them (Sullivan, 1994).
Table 5

Strategies to Manage the Illness Experience

- seek involvement of the mental health system
- come to understand the illness
- accept the illness
- recognize early warning signs of relapse
- comply with medication
- monitor stress level
- inform people of concern - family, friends, trusted school personnel
- try and educate family members and close friends about the illness
- do yoga, relaxation, exercise, eat proper diet, etcetera
- employ positive self-talk
- if necessary, take time away from studies (reduce activity level for an afternoon, a few days)
- withdraw from school, albeit temporarily when in relapse
- use humour
Core Category: Shifts and variations: integrating mental illness and education

As the findings in this chapter indicated, there was an ever present interaction between the university experience and the illness experience. Mark commented:

If I have a good class, I’m usually in good health, and if I’m in good health, I’m usually quite happy. If I come home from a bad exam, it affects my health because there is more stress coming from school.

How the students integrated these two experiences into their lives affected the meaning that they attributed to their university education.

The Effect of Illness on Meaning of University Education

Students with psychiatric disabilities come to university with their own unique biographies, their own specific illness, and their own methods of managing their illness. It is not surprising that the meaning of their education differed markedly from the general student body in that it was greatly influenced by the presence of the illness itself and by fluctuations in the symptoms. The unpredictability of the illness had a drastic impact on the students’ ability to function consistently and effectively, both academically and socially. Living with a mental illness, they had to “take each day as it comes,” focusing more on short-term rather than long-term goals for their education. As Bob stated:

I try and keep the goal in mind, but things fluctuate and I have to drop a course here and there; I have an idea of doing something but it may fall through; the workload changes; sometimes I get sick and I have to go into the hospital.

Shifts in Meaning of Participants’ Education Related to The Illness

The students referred to the unpredictability of their illnesses as “peaks and valleys” or a
"roller coaster" experience. Shifts in meaning of what their education meant to them were, therefore, on a continuum, the location of which depended upon the nature of their illness at a given point in time. For Sid, "The meaning changes all the time and gets lost when I am in a low period." Bob's "good moods" enabled him to imagine having a profession, while during his low periods, he questioned whether his illness would impede his ability to complete his degree. Although Mark stated that he lets matters "roll off my shoulders," he did not deny feeling "discouraged" when having to withdraw from a course, having put so much effort into his studies. Mental health issues were always "consciously" in the background and could never be ignored. In a previous study (Weiner & Wiener, in press) investigating the specific reasons why eight students with psychiatric disabilities decided to withdraw from university temporarily, participants overwhelmingly responded that, in spite of the provision of appropriate educational accommodations, when their mental health deteriorated, their academic concerns became a secondary issue. In the present study as well, the participants agreed that their mental health took priority over their education, for without emotional stability, they were unable to study effectively.

Shifts in Values

Confrontation with major difficulties such as bereavement, abuse or chronic illness can offer new meaning to a person's life. All of the participants felt that their values and attitudes had changed by the development of their illness. For example, Bob thought that he was less hard on himself than he had been before he became ill. Jeff felt that his coping skills had improved and that he was a stronger person because of his illness. Mark's wish to help people had increased since he experienced "how people can be hurt by the mental health system." Sid has learned to appreciate the quality of his education rather than the competitiveness of it. Mary learned the importance of
taking one day at a time and not overtaxing herself. As a result of her breakdown, Anne was learning to be less driven than she had been before. Doug had deepened his understanding of what mental illness is and had become able to seek out treatment for himself.

**Against All Odds**

One of the main threads evident throughout my study, from the point of data collection, to final analysis and write-up, was just how much these students are struggling. Sid believed that his depression had such a global impact on his life that, unless he could come to function consistently, he would be unable to sustain a career in the computer field. Their illnesses affect, not only their experiences at university, but have a profound impact on their everyday lives. The unpredictability of their symptoms affects their energy levels, their ability to plan activities and follow through on those plans. Taken for granted life tasks such as “choosing what t-shirt to wear,” leaving one’s residence and travelling to university, “finding a job,” can become magnified. Constantly facing stigmatization, they are having to battle their negative self-esteem, often hesitant to ask for help or wondering “have I made this up.” The prolonged nature of the illness causes feelings of discouragement, when university tasks take longer to perform. Relapses can limit their own activities and social world. Despite the “road being harder,” they still go on: in the words of Omer, “keep up that fight and hope.”

**Comparison With Other Students**

In comparing themselves to other students, the participants felt that they were just as intelligent, but that it would take them longer to complete their degrees. Doug was convinced that, had his illness not interfered, he would have been as able as any student applying to medical school.
Bob commented that he might have pursued a law degree were it not for his illness. None of the participants felt that they were less competent intellectually than the general population of students.

When they read the personal histories that I wrote, several participants wanted to be assured that the material conveyed just how overwhelmed they felt by “life stresses.” Any information they added to their profile was specifically related to more detailed information about their symptoms. Doug observed, “We all go through periods of feeling down. The significant difference was the length of time, the severity of the symptoms and the degree to which they interfered with my functioning.” He wanted me to know that he engaged in compulsive behaviours at least six hours a day. Omer reminded me that his anxiety is constant and never goes away. Anne reiterated that she experienced “multiple traumas” in her life. Sid informed me that he is sometimes incapable of working for months at a time. Bob added that he can only study for twenty minutes before needing a break, and that his mind wanders during lectures, tests and examinations. In spite of the many obstacles, however, the participants remained motivated to continue their studies. With a positive identity as university students, these students and others like them, can move beyond the limits imposed by their symptoms.

**Advice to Other Students**

The students were specifically asked what advice they would give to other students with a mental illness. They felt it was important that people in a similar situation get to know the resources available to them on campus and to make use of those resources. Letters to faculty identifying their specific learning needs were seen as particularly beneficial. Although it was harder for them to follow their own advice, they cautioned others to focus on their strengths, to persevere and not lose hope; to see the illness for what it is and not as a personal failing. They advised their peers to set
realistic goals. to take a reduced course load. to recognize early warning signs of relapse and seek treatment in the community. They all felt that it was important to know one’s own limitations, to withdraw if necessary and return at a later date. The participants unanimously agreed that it was important to have effective strategies in place to deal with stress. Table 6 lists their words of advice for other students in a similar situation.

Support Systems

Social Supports

The participants’ social support system of friends, family and therapists also played an important role in the meaning that education had for these students. How the participants managed both at university and in their daily lives depended, in part, on the kind of social and emotional support they received in the community.

i. Friends

The participants spoke of the positive role that friends played in their lives. Anne viewed herself as “lucky” because her social network was strong. “My friends pulled me through in a lot of cases.” Mary described two girlfriends who were very supportive. “They help me spiritually and they give me incentive to want to go to school. One of them has had an illness. the other one is married to a pastor.” Bob and Mark were still in close touch with friends from high school. Doug’s friendships he made on campus extended to off campus activities. They taught him to cook and canoe. Sid felt emotionally supported by the couple with whom he was living. Omer valued his continued outside contact with two students whom he met through the support program and who were no longer on campus.
Table 6

Participants’ Advice for Students with Mental Illness

- get to know the system (different departments on campus and established procedures and policies)
- plan courses that you will enrol in well in advance
- make use of available resources on campus
- make use of available resources off campus
- bring matters to the attention of instructors
- send letters to professors (makes concerns more bona fide)
- let your instructors know that you are working on your problems
- develop effective coping strategies
- recognize signs of relapse/keep people informed
- obtain treatment in the community
- know your limitations
- take a reduced course load
- start small
- do not bite off more than you can chew
- break down tasks into small manageable chunks
- do not over extend yourself
- do not be afraid to ask for extensions
- do not feel like a failure
- if you have to withdraw, you can always return
- focus on your strengths
- know your weaknesses
- have established goals
- persevere (do not give up)
- see illness as an illness and not as personal deficiencies
ii. Family Support

Anywhere from 41-65% of individuals with mental illness have been described as living with their families (Goldman, 1982; Skinner et al, 1992). Four of the participants, Omer, Mark, Bob and Doug were living with their families. Anne, Mary and Jeff had close contact with their families, though they were not residing with them. Sid’s siblings resided in the United States.

ii. a. Positive Reactions to Family:

Bob and Mark spoke exceptionally highly of their family’s support. Mark appreciated their non-intrusive concern. Both students viewed family support as essential in helping them to cope. They described their parents as respecting their independence. Although Bob and Mark seemed to have the most effective coping strategies for dealing with their illness, they were protective toward their parents and tended to report primarily “good news” to them, except when they needed to be hospitalized.

ii. b. Negative Reactions to Family:

Omer gave the impression that his family’s way of interacting, although not causing the illness, had played a role in his difficulty in accepting it and developing better coping strategies. He reported that, on several accounts, he did not feel emotionally supported by his family. He did not think that his sister and mother understood or accepted the biochemical aspect of his illness and that he was trying his best to function despite it. “My mother tries to hurry me up and that only interferes and makes me more anxious.” He described his family as “robbing him of time and energy.” Neither Mary nor Anne felt that their families provided them with the kind of encouragement that they felt they needed. Doug did not feel supported by his family and relatives, yet he was sensitive
to his parents having to bear the brunt of his problems. He poignantly described wanting to be the “prodigal son,” who would eventually “do better in their eyes.”

ii. c. Families as Allies:

Although this study did not focus on the role of the family, it is certainly an area that warrants further investigation in terms of the impact of its support on the students’ functioning at university. Families of the mentally ill have been described as “the single, largest group of caregivers providing financial, emotional and social support” (Trainor et al. 1993, p. 12). Family contacts were an important factor in the participants’ abilities to deal with their illnesses and the stresses at university. A model of service delivery that includes the family as an effective resource system, and one in which the university has a role to play in identifying university stressors to relatives, needs to be considered (Weiner, 1996).

Psychological Supports: Role of Therapists

Although all of the students were receiving support from the mental health system, these associations had not necessarily been easily established. Mark was refused admission at three general hospitals before he was finally accepted at a psychiatric hospital. It was the counselling centre’s consulting psychiatrist who finally diagnosed Doug as having an obsessive compulsive disorder. He became so frustrated with waiting lists that he did not remain consistently motivated to find himself a therapist and did not engage in the therapy he needed until he was close to graduating.

The participants in this study represented individuals who were receiving a variety of clinical supports. Mary, Jeff, Bob, Mark and Omer each had a psychiatrist to monitor their medications and another therapist (i.e., doctor, psychiatrist, occupational therapist or social worker)
to engage in psychotherapy or case management. Anne and Sid were being seen by doctors who both monitored their medication and provided psychotherapy. Sid's therapist decided to return to general medical practice and he was left seeking another source of treatment. This hiatus in therapy, plus financial and housing concerns, precipitated a major relapse.

Except for Mary, who had difficulty drawing the line between her support system on and off campus, most of the participants had a sense of the difference between the role of their therapists and the role of the university advocate. Perhaps if Mary had had a consistent therapist with whom she felt well connected off campus, rather than a series of different workers, her need for such intensive emotional support on campus would have been lessened.

Mary and Jeff made the most extensive use of campus resources. They were also the only two participants who were diagnosed in the 1970s, during the era when hospitalization was more the norm than community support for persons with a mental illness (Simmons, 1990). As a result, they were well identified with the community of “psychiatric survivors.” Still, both would have preferred to be more self-reliant. Jeff indicated that his fear of pursuing a masters degree was “having to depend on his professors as I have been all along.” Mary commented: “If I didn’t have an on-going illness, I wouldn’t have to rely on the counselling centre. As it stands, I need all the supports.”

Mental health professionals who listen and encourage their clients have emerged in other studies as playing an important role in helping persons cope with a mental illness (Orrin, 1994; Sullivan, 1994). It was not only important to the students that they have a good rapport with their therapist, but that the therapy was meeting their needs. Anne, Bob and Mark, all of whom had a good rapport with their therapists, made more instrumental use of the support systems on campus. Mark saw both his psychiatrist and his social worker as proud of what he could accomplish and felt
supported by them. Bob respected his doctors' knowledge about his illness. They helped him with his medication and stress levels. Anne felt that she could see changes in her behaviour between the first and second interview four months later. She did not think she was quite as driven and attributed this change in part to her therapy.

Omer, who had difficulty confiding in others. Sid, who experienced a change and a hiatus in his treatment. Mary, who had frequent changes in community workers, and Doug, who had no therapist until the end of his final year, all made more regular and extensive use of individual counselling sessions with the university advocate. Although Omer did not feel that he was benefitting from the unstructured psychotherapy he was receiving on a regular basis, he found it difficult to confront his therapist and discuss alternatives. “If you see someone for a long time and don’t make much progress, you feel guilty because you think it is your fault and that he won’t want to see me anymore.”

Having become involved with the mental health system late in his academic career, Doug felt that he had finally found a treatment approach that worked for him. Unlike Omer, who had put a great deal of hope in the medical establishment. Doug believed that “you have to take control of yourself and your treatment if you hope to get better. You have to take an active role in your recovery.” In a previous study (Weiner, 1996), the mental health system figured prominently in the ability of students with mental illness to function effectively in the student role. They remarked how education about their illness from professionals within the mental health system helped increase their own and their relatives’ understanding of their illness, which was instrumental in improving family communication.
Limitations and Strengths of Study

A limitation of the study was the relative homogeneity of the participants. Two students were women, six were men. Only one student, Omer, was from a different cultural background. I cannot, therefore, make any comments in regards to gender or ethnicity. Neither can I assume that the findings in this study hold true for other students with mental illness at other universities. Glesne and Peshkin (1992) remind qualitative researchers that the answers to many questions are context bound. I am aware that I am not speaking about all university students with mental illnesses, but about these specific students who self-identified to the counselling services of this particular large urban campus and with whom I had formed a close relationship.

A strength of my findings was the relative length of time in which I gathered the data. The longest gap between interviews was six months. This time frame allowed for shifts in meaning to occur. Doug said: “It’s hard for me to consider a time when things go well because things aren’t going well.” At a later interview he felt considerably more optimistic and less discouraged with himself. In addition, the personal histories derived from the transcripts allowed for an in-depth understanding of the participants’ worlds. The students’ comments on both their transcripts and personal histories provided useful information to the research as well as to the students themselves. After having read her transcript four months later, Anne said that she saw more of her strengths. “I was thinking how articulate I was. It goes to show how mood does colour one’s perception.” Mark felt that from reading his transcript he became aware of how well he was able to express himself. When reviewing the account of her personal history, Mary commented that students who are recently diagnosed with a mental illness will have to learn as she did that “it will take longer than they might expect to get their degree and they have to learn to deal with it.” When reading his personal history.
Bob had a difficult time separating the research data from what had transpired in his life on campus since that time. A longitudinal study would take such factors into consideration and provide even greater benefits.

There is no finality to a qualitative study. This thesis is only a partial mapping of the work that has to be done in helping to integrate students with mental illness into the university environment. The voices of professors, family members, friends, service providers, financial and educational policy makers at the federal and provincial levels and many others with whom these students interact directly and indirectly have yet to be heard. These gaps afford the researcher and interested readers the opportunity to continue to explore a wide range of issues with a relatively new population of students who are appearing on our university campuses.

Some of my own areas of interest include: investigating the needs of students who are at university for a time limited period versus those students who are attending for an unlimited period of time, to ascertain if there is indeed a different model of service delivery that is required for these two groupings; developing psycho-educational workshops for the families of these students, where an exchange of information between families and the educational system would benefit all concerned; learning more about the effects of mental illness on academic performance (e.g., difficulties with memory, concentration, focusing and processing information). Such knowledge may result in the delivery of more comprehensive educational supports; and exploring 'severity' of illness from the standpoint of the students' self-perceptions, their families' perceptions and their therapists' perceptions. What benchmarks would emerge as criteria of severity? How might this information inform educators and the students themselves about how to best manage as university students and possibly change the level of service that is currently being provided?
CHAPTER 6

CONCLUSIONS AND IMPLICATIONS

Implications for the Researcher

As a service provider working with university students with mental illness, the model that emerged portraying the trajectories of the students’ educational and illness experiences has not only deepened my understanding of their day to day struggles and triumphs. It has also helped to clarify my understanding of my own personal experiences in working with these individuals. I found that I confronted my own biases, having often wondered why, if school was so stressful for them and often exacerbated their symptoms, they did not select an easier path such as auditing courses or registering with the continuing education department at the university. I began to reflect on my own goals for my educational pursuits in mid-life, when I too could have pursued an easier route. They showed me, through their persistence and their courage, not only how important their education is for them in terms of joining the mainstream and helping their recovery process, but just how important education is to providing those of us who pursue this path, with a purpose to our lives. Inadvertently, the shifts in meaning of their education produced shifts in my perceptions of the meaning of education, not only for these particular students, but for all students, myself included. The participants helped me to appreciate the importance of not losing sight of ones’ inner goals in light of external pressures. There were many days when I questioned my own motivation for pursuing my doctoral studies. The students taught me how important it is not to lose sight of one’s dream, in spite of the hurdles, and to view all struggles as part of the trajectory of life with its constant shifts and variations.
Implications for the Participants

Generally, the students viewed their participation in the research study as therapeutic and empowering. In reviewing his transcripts, Mark felt that he presented himself well. Seeing his words on the written page helped confirm his decision to be at university. Mary said that she was able to appreciate how far she had come in terms of her personal struggles and that she was proud of her accomplishments. Anne stated that the interviews helped her to find a “new identity.”

Before I saw my depression as something bad. I didn’t think that I deserved accommodations unless I was really sick. I realize now that I am different from others and that this difference gives me strength.

Implications for Broader Practice

One of the key findings of this study is the emergence of different student groupings along a continuum: those students with psychiatric disabilities who are more goal-oriented in their learning, and those students who regard their university education as ‘continuing education’. Service providers need to be aware of and sensitive to the purpose of the students’ education and its impact on service delivery. Do students with psychiatric disabilities, for example, whose learning is more time limited and goal oriented, require a greater push and stronger encouragement to complete their degrees? Would peer support groups that incorporate a mutual self-help model, facilitated by the students themselves, better meet the needs of some of these different student groupings? The students, as well, need to be cognizant of the purpose of their education. Students who place less emphasis on getting a degree within a specific time frame may become more relaxed and less stressed in regard to their studies, by having a greater self awareness of the meaning of their education. Omer, who withdrew from university to attend a structured social and vocational
program, recently visited the campus, wanting to discuss his intention to return to university in the near future. Interested in the findings of my thesis, he was intrigued to learn about other participants who are pursuing a university career without a specific time frame or career goal in mind. He felt that that he would be more relaxed and benefit more from the experience were he not to place himself under self-imposed pressure of having to complete a degree. This model has implications for other students with mental illness who sometimes have difficulty giving themselves permission to pursue their education at a slower pace. Hopefully it will help them to see their lives on a continuum and to normalize the shifts in meaning of their education.

Many students with psychiatric disabilities attend university for the social experience and to be in a normalizing environment. Professors cannot assume that every student in their class is attending university in order to pursue a degree. Not all students, in fact, come to university to obtain a diploma (e.g., Kerka, 1989: Otuya & Mitchelle, 1994). Sid's comments of having a different status for students with psychiatric disabilities, and any other students for that matter, who are at university for an education at their own pace and who do not want to compete with other students, is an idea that is worthy of consideration. At present, the structures in place in higher education do not readily allow for these individual rates of learning. If we want our universities to be truly accessible, we need to develop policies based on a different set of assumptions, ones that incorporate the lived experiences of students who are different.

In asking students with mental illness the meaning for them of their education, it is important to consider the meaning of education, not only for other students with chronic illnesses, but for any university student. Doug commented: “University is a place for the exchange of information and that should be the priority rather than the ranking of students and propagation of hierarchies and
cliques.” With a less competitive and time driven academic semester system, words such as ‘dropout’ and ‘special needs’ could be eliminated from our mainstream thinking.

Recommendations

Tinto (1975, 1982, 1993) described the integration of traditional students into post-secondary educational institutions as involving a complex and dynamic series of interactions among students’ personal characteristics (e.g., family background, motivational level), faculty, staff and administration. Certainly for students with mental illness, the concept of integration is further compounded by the way their illness manifests itself at a given point in time. New and dynamic approaches need to be developed, where the services they receive become an intrinsic part of the educational system.

It will take these students longer than students from the general population to complete their degrees. Accommodations, therefore, have to be thought of as more than extensions on assignments and extra time in which to write examinations. Unfortunately, the educational system sometimes does not allow for different stages of recovery and expects the student with a mental illness to know what his or her limitations are. Often the student is penalized financially for having to withdraw from courses prematurely. It is therefore not enough to have flexible admission policies. These policies must be sustained and modified throughout the students’ stay. Doug stated: “There has to be more flexibility, not just in relation to deadlines, but getting into courses, dropping courses. When a student with a mental illness does this, it is not for frivolous reasons.” Whether students with mental illness attend university for what they anticipate will be a limited period of time, having a specific educational goal in mind, or an undefined time frame, their personal circumstances
are constantly changing because of the fluctuating nature of their illnesses. Values of competitiveness and time restraints do not work for people who experience frequent relapse.

As more universities are opening their doors to students with mental illness, attitudinal barriers embedded in current educational practices need to be challenged. Studies have indicated that a significant factor in changing people's beliefs about persons with mental illness is direct experience (Lyons, 1991; Nosse, 1993; Marcus & Davis, 1994; Roman & Floyd, 1981). One way to change the social distancing that many of the participants described would be to develop a mentoring system, as Doug suggested. Although he was referring to faculty mentors, it could well include mentors from the general student body. Through such direct contact, students with mental illness might come to be viewed more favourably. This less formal approach would also help reduce the intimidation that many of the participants described feeling in social interactions with faculty and their classmates. Peer contact could be especially productive for students like Mary and Jeff, who foresee themselves as spending many years in the university environment. It may help to increase their self-confidence, expand their social network and reduce their stated concerns about their reliance on the formal supports on campus. These mentors would need to receive specific training and support in order to become familiar with the social and emotional needs and concerns of students with mental illnesses.

Many people with mental illness live with a constant fear of being discovered (Weinstein, 1982). The participants felt apprehensive about how faculty and peers would react if they found out about their mental illness. Stein et al (1992) described a creative use of academic programming through a university based practicum course on social relationships. Comprised of individuals with mental illness from the community and undergraduates from the university, the major goal of the
program was to create a social milieu that encouraged a greater understanding and appreciation for differences. More hands-on collaborative partnerships that would produce greater interaction between faculty, students, and students with mental illness, need to be established. Studies such as this demonstrate how universities can utilize their resources creatively without compromising academic standards.

It has been suggested in the literature (e.g., Conradi, 1993) that office hours be extended for adult students. This recommendation applies equally to students with mental illness, who often function better in the afternoons and evenings, when the side effects of their medications have worn off and they do not feel as drowsy. Bob, Mark, Doug and Mary thought that there could be a role for families involvement with their education, mainly in the area of explaining the stresses at university and how they can exacerbate the symptoms of their illness. Most of the participants felt intimidated by the largeness of the campus in terms of geographic size and numbers of people. Perhaps if more resources and support services were allocated to smaller universities that are not urban based, more students with mental illness would have the opportunity to expand their social and intellectual world in an atmosphere that is more familiar. As it stands now, through lack of funding, many of these smaller institutions do not have the appropriate facilities and resources, both on their campuses and in their local communities, that can provide the academic as well as the psychological support that students with mental illness require to pursue their educational goals.

**Conclusion**

*It's nice to know that somebody cares. It's nice to feel that the experience here may be used to help somebody else. It justifies it all, that it's not just disappearing into the void of time, that somebody is going to take from it and distill some meaning from*
it, that it can be applied to other persons and that this can be made a better environment and that I can be part of that. As I was trudging through all those years, that’s what I wanted to be able to say, that I can change this and that I can help other people so that I don’t just get crunched through the system, spat out at the other side and totally have no effect on it all. If I can help to change it, then I will have triumphed. It will all have been worthwhile. I can look back and say I wasn’t processed. I made a difference. If you could take this information and educate people more and change the system, how it looks at people with mental illness and make it a friendlier place for people with mental illness.

(Doug’s comments on the research process)

Although this is the end of my thesis, it is the beginning of an opportunity to develop innovative post-secondary educational practices for students with mental illness. During the data collection and analysis, I realized that if I were truly to listen to the words of the participants and to take their thoughts and feelings seriously, I would have to act upon what I heard. I wanted their words, instead of remaining silently on the pages of my thesis, buried on a library shelf, to be mobilized into a change in educational practices. Very quickly, on Bob’s suggestion, I was able to arrange for priority enrolment for the students with whom I work. In addition, I have started a peer mentoring program, matching students with psychiatric disabilities with a “buddy” from the general population of students. I have also begun to organize a sub-committee of select members of the university’s advising and advocacy group for students with disabilities, to investigate policies and practices that need to accommodate the constant shifts in meaning of education for students with mental illness. Procedures need to be developed that allow for these students to circumvent the
repetitive petitioning process. In addition, more flexible time-frames for course work requirements need to be established.

In the literature on retention/withdrawal of post-secondary students, there is a tendency to treat minority groups as identical, when in fact they differ in terms of their attributes and educational needs. To date, there is no model available to guide research in this area for university students with mental illness. I hope that this conceptual model of the meaning of education for students with mental illness will result in more creative and flexible ways of working with this population on our university campuses. (See Table 7 for a list of preliminary suggestions composed both by the participants and myself, on how to address some of the needs of this diverse group of students.)
Table 7

Suggestions for Revamping Educational Policies, Practices and Procedures

Participants' Suggestions
-seminars for family members, relatives and friends on the interaction better the illness and the demands of university
-priority registration for all courses on campus
-a structure that allows for extensions on course work where the student does not have to petition on a continual basis
-a separate category or status for students who do not want to complete their degree in a way where they have to compete with other students
-broader time-frames in which to complete the academic year work
-seminars on mental illness that faculty, staff and students attend, with students with mental illness themselves in attendance
-more faculty advisors to assist with academic integration

Researcher's Suggestions
-research to gain a better understanding of the impact of various mental illnesses (including side effects of medication) on academic performance
-deployment of resources to smaller universities
-guaranteed financial reimbursement if withdrawal from a course is due to illness
-credited courses where students with mental illness and students from the general student body work cooperatively and come to understand one another
-trained volunteers (mentors) to spend time with these students on campus
APPENDIX ‘A’

Ontario Human Rights Code

Every person has the right to equal treatment with respect to services, goods and facilities without discrimination because of race, ancestry, place of origin, citizenship, creed, sex, sexual orientation, age, marital status, family status or handicap.


"Because of handicap" means for the reason that the person has or has had or is believed to have had any degree of physical disability, infirmity, or malformation that is caused by bodily injury, birth defect or illness and, without limiting the generality of the foregoing including diabetes mellitus, epilepsy, any degrees of paralysis, amputation, lack of physical co-ordination, blindness or visual impediment, deafness or hearing impediment, muteness or speech impediment, deafness or hearing impediment, or physical reliance on a guide dog or wheelchair or other remedial appliance or device, or a learning disability, or a dysfunction in one or more of the processes involved in understanding or using symbols or spoken language, or a mental disorder.

APPENDIX ‘B’

Description of Services

WHO IS ELIGIBLE?

Any part-time/full-time York University student who:

1. is receiving on-going care from a mental health professional in the community.

2. may be experiencing difficulty adjusting socially and/or academically to the university environment.

3. may be taking prescribed medication.

SERVICES PROVIDED

1. Assessment of needs on campus.

2. Orientation to resources on campus. e.g., admissions, course advising. financial aid. career counselling.

   Workshops on reading. writing. study skills. time management. stress management.

3. Individual counselling/resource management.

4. Orientation to campus facilities. e.g., libraries. athletic centre. clubs and societies.

5. Peer support/weekly group meetings.


7. Linkage to community resources.

APPENDIX ‘C’

Letter of Consent

Dear ________________(Name of Participant)

I am writing to request your participation in my doctoral thesis which I am undertaking in connection with my studies in applied psychology at the Ontario Institute for Studies in Education at the University of Toronto.

As you are undoubtedly aware, with greater community support for persons with continuing mental health concerns, and the introduction of improved medications, an increasing number of students with on-going mental health needs are able to attend university for the first time or return to their previous studies.

I am keenly aware that each person is the best expert of his/her own personal experience. I plan to interview a number of students with continuing mental health needs, asking them what their university education means to them: their reasons for being at university; what their experiences have been, and what their hopes and aspirations are regarding their education.

You are in no way obligated to participate in this study. If you are interested in participating, please fill out the consent form enclosed. Declining to participate will in no way affect the services you are receiving at the university. Please do not hesitate to contact me at (telephone number) if you have any questions.

Sincerely,

Enid Weiner, M.S.W.
APPENDIX 'C' CONTINUED

Letter of Agreement

I agree to be interviewed for approximately 1-1/2 hours in Enid Weiner's office, regarding my pursuit of higher education.

I agree to be interviewed again, if necessary, in order to clarify aspects of the initial interview.

I agree to have my interviews audio-taped and to have them transcribed and analysed.

I am aware that all identifying information will be deleted and/or modified in order to protect my identity.

I am aware that I am free to withdraw at any time from the study for any reason whatsoever. My withdrawal will not affect the services I am receiving or will continue to receive from the university.

I agree to have the findings of the study published. All names and any other identifying information will be changed so that anonymity is guaranteed and confidentiality assured.

Date________________

Signature________________________________
APPENDIX ‘D’

MAIN CATEGORY: #1 UNIVERSITY EXPERIENCE: Education/Recovery Continuum

Sub-categories and Properties

Meaning of Education
normalization (alternative roles, part of mainstream)
structure (focus, routine, goal setting)
hope (motivation, empowerment)

Barriers to Learning

Technical
physical size of university
number of students in classes
not obtaining courses of choice
lack of availability of professors
lack of financial assistance
lack of comprehensive advising
having to meet academic deadlines
negotiating the university bureaucracy
line-ups

Medical Barriers
illness as a barrier (physiological effects, fluctuations in symptoms)
treatment of illness (e.g., waiting lists, ineffective therapy)
side effects of medications
status as a student (interruptions, pace of learning, part-time attendance)

Social Barriers: External
ignorance about mental illness in university community
attitudes of faculty, staff, and students
family’s lack of understanding and acceptance
friend’s lack of support
lack of mental health support
educational policies and procedures (repetitive petitioning, privilege versus right)

Internal Social Barriers
internalization of stigma - fear, doubt, shame, encouragement
fear of disclosure, asking for help, risking socially

Educational Barriers
status of special needs student
right versus privilege
continual petitioning
APPENDIX 'D' Continued

MAIN CATEGORY # 1 UNIVERSITY EXPERIENCE: Education/Recovery Continuum

Categories and sub-categories

Supports to Learning

Academic
support services for students with mental illness (letters to professors identifying learning needs, academic accommodations such as separate rooms and extra time to write examinations, extensions on assignments)
learning skills workshops (reading, writing, note-taking, time management)
educational policies and practices (university policy for students with disabilities, opportunity to extend course work beyond academic term if necessary)
financial assistance for students with disabilities

Social/Emotional
counselling
advocacy services for students with mental illness
informal peer support
peer support group
understanding instructors and staff
knowledge of mental illness in university community
support from family, friends, therapists (encouragement)
medication (increase in self-confidence and social interaction)

Inner Resources
inner strength
knowing one's strengths and limitations
understanding and accepting one's illness
effective methods to handle demands of university (avoidance of early morning classes, identifying concerns to appropriate people, accessing resources on campus, taking reduced course load)
APPENDIX ‘E’

MAIN CATEGORY # 2 ILLNESS EXPERIENCE: identity/coping continuum

Manifestations

**affective**
- anxious
- nervous
- depressed
- afraid
- overwhelmed
- discouraged
- inadequate

**cognitive**
- thinking skills (obsessive thoughts, hearing voices, paranoia)
- ability to make decisions (courses to take, when to withdraw)
- reading/writing
- organization/planning/time management
- short-term memory, processing information
- motivation

**behavioural**
- getting to campus
- pace of learning - length of time to complete work
- studying effectively
- socializing (initiating social interactions, misperceiving social cues)
- coping skills (ability to handle work, meet deadlines, manage stress of student role
- behaviour in class (excitability, interrupting, overreacting, loud voice, obsessiveness)
- energy level (fatigue)

**medical**
- side effects of medications (tremors, nausea, thirst, fatigue, blurred vision, dyskinesia)

Management of Illness

a) **Identity Over Time**
- stigma of mental illness (externalized- response from others
  - internalized - self perceptions, self-esteem)
- self-disclosure
- comparison with other students
- “against all odds”
Appendix ‘E’ Continued

MAIN CATEGORY # 2 ILLNESS EXPERIENCE: identity/coping continuum

b) Performance of Daily Activities
   coping strategies (accessing supports of mental health system, recognizing early warning
   signs of relapse, knowing how to handle illness such as compliance with
   medications, reducing activity level when necessary)
   advice to other students

Support Systems:
   family
   friends
   mental health system
REFERENCES


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