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Concerns and Needs of University Students with Psychiatric Disabilities

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Abstract

A needs assessment employing individual interviews was administered to 24 university students with psychiatric disabilities. All of the students were participants in an on-site, supported education service for students with psychiatric disabilities. Five themes were identified as areas of concern: problems with focusing attention and organization, low self-esteem, problems with trust, stigma, and high levels of stress. The findings point to the need for comprehensive services for this particular population of students. The importance of a peer support group and a one-to-one relationship with a counselor and an academic advisor were seen as essential, in addition to career counselling and academic accommodations.

Introduction

Anthony, Cohen, and Farkas (1990) described persons with psychiatric disabilities as having "diagnosed mental illnesses that limit their capacity to perform certain functions (e.g., conversing with family and friends, interviewing for a job) and their ability to perform in certain roles (e.g., worker, student)" (p. 4). With the deinstitutionalization movement and the introduction of more effective medications, many of these individuals are able to either become university students for the first time or return to campus following recovery from their illness. Students with psychiatric disabilities, however, remain a relatively unknown and unstudied population in terms of their experiences on our college campuses.

Three types of supported educational programs for students with psychiatric disabilities are discussed in the literature: self-contained, mobile and on-site (Unger, 1992). In the self-contained model, individuals recovering from mental illness attend non-credited classes, typically on a college or university campus. Emphasis is placed on personal development, vocational planning and academic upgrading. Former participants in self-contained programs may find a link to a larger educational setting through a mobile

support team, or they may become involved with an independent on-site program at colleges or universities of their choice. The on-site model provides support to students with psychiatric disabilities through a staff person designated by the institution to work with these individuals. All three models share a common purpose - to help these students achieve access to higher education in a manner in which they can experience success.

Therefore, the purpose of this study was to ascertain the perceptions of students with psychiatric disabilities in an on-site program regarding their concerns and the types of accommodations and supports they require. One of the objectives of the study was to provide students the opportunity to play a major role in shaping their support service and to become their own agents of change.

Literature Review

Until the 1980's, needs assessments of postsecondary students were primarily conducted with the general student population. These needs assessments tended to be close-ended, mailed questionnaires or telephone surveys (Harman, 1971; Kramer, Berger, & Miller, 1974; Lopater & Hursh, 1972; Storrs, 1972; Strong, Hendel, & Bratton, 1971). These studies indicated that students were concerned about academic issues, career identity and planning issues, financial issues, and personal and social issues. The relative weighting of these areas of concern differed from study to study, possibly a result of differences in sampling and measurement techniques.

Since 1980, needs surveys have moved beyond assessing general student needs to include specific subgroups such as deaf and hard of hearing students (Khan, 1987; Petronio, 1988; Rittenhouse, 1989; Warick, 1992) and students with learning disabilities (Brinckerhoff, Shaw, & McGuire, 1992; Lundeberg & Svien, 1988; Siperstein, 1988). Compared to the general student population, students with disabilities have their own special needs that require accommodations. Although some of these needs are common to disability groups in general (e.g., extensions on assignments, adaptations of modes of learning), each disability group may exhibit unique needs depending upon the nature and severity of the disability. Furthermore, within any given disability group there are individual differences among students with regards to their needs and concerns.

Three needs assessments have been published on postsecondary students with psychiatric disabilities. Unger (1991) conducted a survey of existing educational programs and found accommodations that were provided to include assistance with registration/financial aid, orientation to campus, modifications to seating, assistance in note taking, tape recording, extended time for examinations, separate room in which to write examinations, workshops on study skills, time management, removal of academic failures from transcripts when appropriate, and peer support. Cooper (1993) reported on an assessment of supports needed for students with psychiatric disabilities. Student services staff, service providers, consumers, and their families were asked for their opinions. The following services were identified as the most essential: academic mentoring, counseling and out-reach services, stress and time management training, peer support, improved dissemination of information about campus services, and increased emphasis on faculty

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

In the present study, students with psychiatric disabilities were asked directly to identify academic and social tasks frequently demanded in the university environment that are of difficulty to them and to identify personal and social/emotional areas of concern.

Method

Subjects

Twenty-four students (11 men, 13 women) participated in the study. All were involved in an on-site program for students with psychiatric disabilities. All participants had been previously diagnosed as having a long-term psychiatric problem by a mental health professional in the community. Their diagnoses were as follows: clinical depression (7), obsessive compulsive disorder (3), manic-depression (3), multiple personality (2), schizophrenia (2), posttraumatic stress disorder (2), psychotic episodes (2), anxiety disorder (1), schizoid/affective disorder (1), and seasonal affective disorder (1).

The ages of the students ranged from 20 to 49. More specifically, 12 were between 20 and 25 years of age, 6 between 26 and 31 years, 3 between 32 and 37 years, 2 between 38 and 43 years, and 1 between 44 and 49 years. Of the entire sample, all but two students were Caucasian. Thirteen had been enrolled part-time (under three courses), and 10 had been enrolled full-time (three courses or more) during the previous academic year. One student was auditing courses in preparation for his return to university in the fall. All students had been enrolled in the Faculty of Arts. There were three in their first year, six in second year, nine in third year, three in fourth year, and three who had recently completed their master's.

Measures

The measures were a questionnaire developed by the first author and an interview based on subjects' responses to the questionnaire. Items on the questionnaire requested that students rate the difficulty of various tasks they faced. Students were also asked to add any needs that were not included on the questionnaire. They completed the questionnaire in an individual session with the investigator who was available to clarify any question they did not understand. Data from the questionnaire are not reported but are available from the first author.

The personal interview was conducted after students completed the questionnaire. Interviews lasted between 30 and 45 minutes depending upon how much each student wished to disclose. Students were also asked to elaborate on answers that revealed an area of concern. Their comments were recorded through process notes under headings

corresponding to the specific items on the questionnaire. These notes were later analyzed qualitatively in order to uncover common themes.

Procedures

All participants were contacted by telephone and asked to respond to a needs assessment questionnaire related to their role as university students. It was stated that the results would likely benefit the counseling centre that was currently serving students with psychiatric disabilities. Students were informed that following completion of a close-ended questionnaire, they would be asked to participate in a personal interview to elaborate on some of their specific responses. Before filling out the questionnaire, participants were presented with a letter reiterating much of what had been said over the telephone. Students were not asked to put their names on the questionnaires and were assured that their personal information was strictly confidential.

Results

In order to obtain a better understanding of the students' concerns, they were asked to expand upon their answers in an individual interview following completion of the questionnaire. Analyses of the interview results revealed five themes or overriding issues that affected their functioning on a variety of academic and social tasks. These issues which were often interrelated were: a) problems with focusing attention and organization, b) low self-esteem, c) problems with trust, d) stigma, and e) high levels of stress. Examples of students' comments are included to illustrate these themes.

Not surprisingly, problems with focusing attention and organization which are presumably directly related to the students' illnesses make some instrumental tasks such as writing essays, doing class presentations, and preparing for examinations difficult. Problems with these and many other tasks from course selection to class participation were compounded by low self-esteem. "I have difficulty with course selection because I often think I won't be able to do the work." "If I miss something during class, I get down on myself. I then can't relax and pay attention or make a contribution."

Self-esteem affected these students' difficulties in performing social tasks as well. "When you get into a depression, people don't want to be bothered with you," said one student. Some described losing many friends as a result of their illness. They mentioned having their confidence shaken after each crisis they experienced.

These students appeared to set high expectations for themselves. In whatever they did, there was the fear of being evaluated and laughed at, and at the same time, not wanting people to be cognizant of their fears. One student said, "I give everything my best shot, and when I don't do well it breaks my self-esteem. I hate being evaluated because I feel I have to prove myself. I experience any failure as I have failed."

Trusting others was described as a very slow process for these students. Social tasks such as developing close friendships, inviting a student to do something with them, or asking a

peer for assistance presented difficulty because of their hesitancy in trusting others. Their fear of embarrassment and shame around their illness inhibited their interpersonal skills. As one student commented, "How do I explain the gaps in my life, why my academic and professional careers have so many interruptions, why I'm on welfare?"

Students' reluctance to disclose their disability to professors was related to both a fear of stigma and their desire to prove that they could do the work on their own. One student observed, "It's hard to disclose at the beginning of the year when I feel I am in control. It puts you off to a bad start." Advocating for themselves was of concern because of what they perceived as the stigma of their disability, "It's one thing to disclose your disability and another to have it understood." However, they recognized it was a skill they needed to learn. One student honestly stated, "It's a safe position not to do it, but not an ideal one." Students expressed the desire to learn self-advocacy skills.

Personal concerns revealed a high level of stress that was related to numerous factors: the nature and chronicity of their illness, fear of relapse, the side effects of medications, hassles with vocational rehabilitation and family benefits workers, social anxiety, lack of friends, therapy abuse, deadlines, and self-disclosure. It is not surprising that in times of crises, these students described feeling overwhelmed. Many were worried about finding a job and living independently, dating, getting married, and supporting a family. One student wondered if a cure would ever be found for his mental illness. Another student with excellent academic standing and a highly responsible job was quick to dismiss her success because she still has a hard time riding the subway and doing daily chores such as grocery shopping. "I'll have to live with my mental illness, even when I graduate from university."

The types of accommodations students saw as valuable may be grouped into five categories: a) an ongoing personal relationship with a counselor on campus, b) peer support, c) career counseling, d) instrumental supports, and e) support from faculty and staff. A personal relationship with a counselor was seen as important in terms of the support provided and the continuity of knowing the same person throughout their university career. Having someone to advocate on their behalf seemed important to legitimize their requests. One student said, "This is the only disability where people are punished for recovering. People then think we don't have a problem."

Students valued peer support in a variety of ways. They felt most comfortable and accepted in a peer support group where they were with "like minded people who are different." They saw a support group as an opportunity to problem solve, learn more about the university environment, form relationships, and not feel so socially isolated. In terms of wanting to be linked with a matched "buddy" on campus, there was no consensus regarding the type of person this should be, They all agreed that the individual should know the university well and understand their feelings of shame and isolation. Participants said they would like to have a place to go on campus between classes where they knew other students, where they could have inexpensive coffee and a study carrel. They wanted a sense of belonging and were looking for a place that felt safe and comfortable where they could be themselves.

Career counseling beyond the current level of service provided on campus was also listed as a high priority. Students felt it would be easier to complete courses if they knew where their aptitudes and interest lay.

Instrumental supports found to be helpful were yearly orientations before the academic year begins including tours of campus and the library, extensions on assignments, and extra time to write examinations. They would have liked access to breaks during examinations.

Participants in the study were much more likely to avail themselves of academic advising services if they had one staff person with whom they could meet over time. Otherwise they often felt reluctant to seek out these services for fear of burdening others. With encouragement from an academic advisor, usually the continuity of contact was maintained.

Discussion

One may argue that many of the needs identified by students with psychiatric disabilities are similar to the needs of the general student population that have been documented in a number of studies (Carney & Barak, 1976; Carney, Savitz, & Weiskott, 1979; Evans, 1985; Henggeler, Sallis, & Cooper, 1980; Kramer, Berger & Miller, 1974; Weissberg, Berentsen, Cote, Cravey, & Heath, 1982). Concerns regarding career direction, time management, study skills, and social skills have been consistently identified by college students. Given that students with psychiatric disabilities in this onsite program were integrated into the mainstream, it is understandable that they experienced similar stresses. However, many of the student population were quantitative studies requiring only a yes/no response; therefore, it is difficult to determine the intensity to which the general student population experiences these difficulties compared to students with psychiatric disabilities.

Principles of psychiatric rehabilitation have emphasized the importance of people with disabilities acquiring skills and support to function in their community, work and educational environments of choice (Anthony et al., 1990). The findings of this needs assessment confirm this statement. Students identified academic skills (e.g., studying effectively, writing essays) and social skills (eg., developing close friendships, joining extra-curricular activities) and a combination of the two (e.g., disclosing disability, advocating for oneself) as skills they were lacking.

Many of the students were afraid to ask for supports, not believing they truly deserved them. "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." In addition, the students' lack of assertiveness may have been related to their lack of awareness of their rights as special needs students. Most had been receiving accommodations and were participating in a peer support group. However, they had a hard time viewing themselves as students with a disability with concomitant rights. Said one student, "I never knew I had a disability until I came to university. I never saw myself as disabled, but rather as having an illness."

Students with psychiatric disabilities receive services through the counseling centre at this university as opposed to the office for persons with disabilities.

Most of the participants in the study strongly agreed that high anxiety, career direction, and self-esteem were areas of concern. Self-esteem is a complex issue that warrants consideration from a systemic perspective. Self-esteem is not simply a characteristic of the individual. It is shaped by the feedback individuals receive from the contexts in which they live, work, and study (Shavelson & Bolus, 1982). Educational policies and procedures derived from a medical model of mental illness (Stone, 1984) contribute to the negative self-perceptions of students with psychiatric disabilities.

Self-esteem and other social and emotional issues were very much related to how the respondents viewed their functioning as university students. Cooper (1993) also found that social concerns and self-esteem issues were prominent in students with psychiatric disabilities. Miller and Miller (1991) reported that for persons with psychiatric disorders almost 50% of the items on 'daily hassles which were rated as bothersome' were "interpersonal in nature and might be interpreted as bearing on self-esteem" (p 47). Further, similar to the psychiatric patients living in the community in Miller and Miller's study (1991), social isolation including problems developing close friendships was a common theme expressed by the university students in the present study.

Wolf and Di Pietro (1992) stated that "supported education programs offer enhanced self-esteem through academic accomplishment as well as increased career opportunities resulting from educational attainment" (p 67). Unger (1990) reported a significant improvement in self-esteem in a self-contained supported education program at Boston University. Though it was not the purpose of this study to measure the impact of intervention on self-esteem, the investigators found in this on-site program that although students had done well academically and some had excellent part-time jobs, they still devalued themselves. Perhaps there is a need to compare models of supported education more thoroughly in terms of their goals to ascertain whether one mode of service delivery is more effective than another.

Students felt that career counseling was a need not being met to their satisfaction. Egnew (1993) described supported education and supported employment as having historically developed as "two separate and distinct services" (p.126). He advocated for an integrated approach of these support systems. Students in this study saw their involvement with vocational rehabilitation workers as a stressor. With a more collaborative effort, educators and vocational rehabilitation counselors can join forces more constructively for the benefit of students with psychiatric disabilities.

Implications

Needs assessments that include personal interviews are an important mode of process evaluation that can lead to changes in the nature of a service. Prior to conducting the present study, students with psychiatric disabilities at this university had a one-to-one relationship with a counselor, were linked with a specific academic advisor familiar with

psychiatric disabilities, and had the opportunity to participate in a weekly peer support group. Additional services, however, were implemented on the basis of student feedback. These include a learning and study skills assessment for each student with more comprehensive learning and study skills workshops available to those who need them, and greater emphasis on social skills development. Future goals include establishing more effective support in the area of career counseling.

Limitations

The results of the present study should be interpreted with certain limitations in mind. It is important to note that participants all attended one university which was situated in an urban centre. All of the students in this study lived off campus, some independently, and others in group settings or with their families. Other needs and concerns might have been identified in settings where most students live in university residences. A second limitation with reference to the procedures employed in the study was that the principal investigator and interviewer was also the coordinator of the on-site support service. Although possible problems that might have arisen from this dual role of service provider and researcher are that students may have been reluctant to make negative comments, and the investigator may have been biased; there were many advantages resulting from this dual relationship. Students indicated that had they not trusted the investigator due to her professional relationship with them, they would not have participated in the study and/or disclosed their feelings so freely.

Given the major social and academic concerns of students with psychiatric disabilities identified in the present study, it is reasonable to suggest that comprehensive services for these students on university campuses are critical if they are to have equal access to postsecondary education. This involves a political commitment on the part of the university and the community at large. Many of the problems that students identified as stressors (e.g., having to explain that fees are late because the family benefits cheque has not arrived; being ineligible for a work study program because the provincial government has made it available only to students with a full-time course load) may also be interpreted as related to powerlessness. Lerner (1986) claimed that powerlessness is such a pervasive part of our lives that it is rarely identified as such. Many of the issues raised by these students go beyond the nature of the disability and the confines of the university. The stigma of having a psychiatric disability is in itself a barrier that increases stress and affects self-esteem and overall functioning. Accessibility of postsecondary education for students with psychiatric disabilities must be approached in conjunction with many sectors of society. It is important to collaborate with these students in order to make changes that enhance their educational opportunities and better meet their needs.

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