

**VERIFICATION OF SELECTED NEEDS FOR CONSUMERS OF MENTAL HEALTH
SERVICES**

by

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**A thesis presented to the University of Manitoba in partial
fulfillment of the requirements for the degree of Master of
Education.**

March, 1992



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ISBN 0-315-77981-0

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Acknowledgements

The authour would like to thank his committee, Dr. D. Harvey, Dr. E. MacPherson, and Dr. F. Drewe for their assistance and guidance.

Acknowledgement is extended to the staff and volunteers at the Society for Depression and Manic-Depression who encouraged the study from the outset and to their members who so generously gave of their time to participate in the study.

Thank you to the staff at the Statistitcal Advisory Centre for their guidance and assistance, availabe to me whenever needed.

ABSTRACT

Hospitalization, until recently, has been the accepted course of treatment for the chronically mentally ill. A more recent focus has been to foster reintegration of the chronically mentally ill into community living. Moving patients into the community has revealed however that adequate services and supervision are non-existent or inadequate to help patients thrive while living in the community.

The purpose of the study was to determine the relationship between perceived satisfaction with employment, social support and medication/treatment and lowered scores of depression and manic-depression as defined by the Diagnostic and Statistical Manual of Mental Disorders, Third edition-Revised. The data collected were analyzed using Kendall-tau b correlations. The Mann-Whitney analysis was used to determine differences between urban/rural dwellers, males/females and age groupings.

A mailed survey questionnaire was sent to all 365 members of the Society for Depression and Manic-Depression. One hundred and fifty-one surveys were returned. Eight returns were not used in the final tabulation. The sample consisted of 83 females and 56 males. The age range for females was from 19 years of age to 80 years and the range for males was from 22 years of age to 69 years.

No statistical differences were detected between rural/urban dwellers, males/females and age groupings. This was consistent with literature reviews. Perceived satisfaction with employment, social support and medication/treatment were significantly related to

mood.

While recognizing the importance of the findings of this study, much work remains in determining the critical attributes and aspects of what is necessary for individuals to exist and thrive while living in the community.

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Chapter 1

Introduction

Until recently, the accepted course of treatment for the chronically mentally ill has been hospitalization or enforced incarceration. A more recent focus has been to foster reintegration of the chronically mentally ill into community living. Moving in that direction, the province of Manitoba has recently agreed to put more than \$2 million into the mental health-care system in order to decentralize services and to move towards community-based care (Weber, 1992).

The push for the movement of the chronically mentally ill from large institutions into the community has occurred within the framework of the general social reform movement of the 1960's (Crosby, 1987). Community treatment was thought to promote independence, ensure support from family and friends and to facilitate the return to "normalcy". Massive deinstitutionalization revealed, however, that there did not exist proper planning for the release of patients nor was there adequate continuing supervision of them in place (Mechanic, 1984). Patients were released from hospitals into the community without adequate preparation and without any consideration of the social costs to the patient and his/her family. As well, a network of appropriate services would not usually exist.

Since the social reform movement of the 1960's, there has been some attempt to address those issues perceived lacking in the adequate support of patients in the community. A review of the

literature reveals a chronic shortage of hard data that details just what is needed for ex-patients to survive and/or thrive while living in the community. One of the more recent foci for determining community needs for these individuals has been the role of consumer involvement, that is, hearing from the individuals directly affected. Mental health is determined to a great extent by the degree of control one has over one's own life. The paradox is that persons who have a long term illness with related functional disabilities are neither allowed to participate in decisions on services or service delivery, nor are they permitted to give meaningful feedback to the system (Pyke et al, 1991). Consumer involvement is necessary to allow individuals some form of control in the planning, development, and delivery of services. Those who deliver services need to hear from the consumer.

Need for the Study

The Diagnostic and Statistical Manual of Mental Disorders, Third Edition - Revised (DSM III-R), describes depression and manic-depression as disorders of affect. The essential feature of these mood disorders is a disturbance of mood where mood refers to a "prolonged emotion that colours the whole psychic life" involving either depression or elation (Papolos & Papolos, 1987). The prevalence of depression in the general population is estimated to be between 5-26% for females and 3-12% for males. For manic-depression it is estimated that between 0.4-1.2% are afflicted, with rates being equal in males and females (D.S.M. III-R, 1987).

Most patients who have a manic episode go on to have multiple occurrences of major depressive and manic episodes. Studies suggest that between 50-85% of patients with a major depressive episode who seek hospital treatment will have at least one subsequent episode of depression in their lifetime (Papolos & Papolos, 1987).

The Manitoba Health Services Commission (M.H.S.C.) has calculated costs in Manitoba for April 1988, to March 31, 1989 inclusive for affective mood disorders. There were approximately 48,570 patient days at \$ 412.69 per day (the provincial M.H.S.C. average per diem) totalling \$ 20,047,654, a significant outlay for just one of the major mental disorders.

The latest figures available, those from 1989, indicate 9100 people in Manitoba on the active case-load of Community Mental Health Services, with an average daily population of 900 in the three mental health centres in the province (Islam, personal communication, 1991). No breakdown on the basis of diagnosis was available. What is readily apparent is that the vast majority of these individuals afflicted with psychiatric disorders are left to cope within the community context.

Only recently have investigators begun to examine how well these deinstitutionalized individuals are managing in the community. Jones (1988) notes, in a review of the practice of deinstitutionalization in the United States, that the question of what actually happens to patients who leave hospital and re-enter the community is largely unanswered. Some of the questions that are finally being asked include: What existing sources of help are

there? Are they being utilized efficiently, if at all? What unmet needs have to be addressed? What problems are not visible to those willing and able to help, especially with regard to policy makers?

Consumers of mental health services have rarely been involved in decisions about service planning, service implementation, or evaluation of services provided. This lack of involvement, combined with the stigma attached to those with mental illness, has led to a situation where services have been increasingly under-utilized (Lord & Hutchison, 1987). As a result, greater numbers of people with chronic mental illnesses have not received services which are beneficial to them and their families; and community leaders are increasingly calling for more relevant services which will lead to better long-term outcomes and greater utilization of each person's capabilities (World Health Organization, 1990).

Service program planning needs to address the consumers of mental health services perspectives on their present functional levels, concerns, and present coping status. This study was undertaken to verify the needs of consumers of mental health services for living in the community with one of the major mental disorders. As Estroff's (1981) study in an American psychiatric setting concluded, "An individual's perceptions, beliefs, feelings, experience and behaviours constitute the most important unit of analysis to understanding any contemporary social scientific endeavour" (p.37). The approach used in this investigation was to recognize the significance of the "participants as experts" so that the data base emerged from their experiences and perceptions.

Statement of the Problem

It has been found that there is a relationship between an individual's involvement with community services and emotional well being (Hutchison, Lord and Savage, 1985). Investigators have begun to examine satisfaction with community services only recently from the consumer's perspective.

Inquiries into the areas concerning just what is needed for successful reintegration into the community have been limited but have identified several factors which appear to enhance reintegration or "normalization". Thus the research question of this study is: "What is the correlation between specific identified social factors and the symptomology of depression/manic-depression?" This question was examined with several hypotheses.

Research Hypotheses

Hypothesis 1. There is a significant correlation between perceived satisfaction with employment and low scores of depression and manic-depression as defined by the Diagnostic and Statistical Manual of Mental Disorders (third edition - revised).

Hypothesis 2. There is a significant correlation between levels of social support and low scores of depression and manic-depression as defined by the Diagnostic and Statistical Manual of Mental Disorders (third edition - revised).

Hypothesis 3. There is a significant correlation between satisfaction with medications and/or treatment regime and low scores of depression and manic-depression as defined by the Diagnostic Manual of Mental Disorders (third edition - revised).

Significance of the Study

The primary goal of this study was to determine how well persons with chronic mental illness were coping in the community. To make this determination, it was necessary to examine the resources and services they presently used in coping with their daily activities and what resources and programs they saw as lacking in the community. The examination of the person's perceived satisfaction with selected community services was guided by reviews of the literature. The findings from this study will be useful to guide future directions in program and policy development.

Procedures

This study used a survey questionnaire developed to examine personal perspectives on how individuals felt their needs were met with regard to employment, social supports, and medication or treatment regimes.

The first survey was sent out to 365 members of the Society for Depression and Manic-Depression on July 10, 1991. A follow up letter including an identical survey was sent out on July 21, 1991 to those individuals who had not previously replied.

The data collected were analyzed using Kendal-tau correlations for Hypotheses 1,2, and 3. The Mann Whitney analysis was used to examine differences between rural/urban dwellers, males/females, and age groupings.

Assumptions of the Study

It is assumed that those who live with a chronic mental illness are the ones most qualified to elucidate and convey the

necessary information about coping in the community and about what is needed to achieve a general feeling of well-being.

It is assumed that with limited time and resources, a mail survey will reach the greatest number of participants and will reveal the necessary and desired information.

It is assumed that a mail survey is a reliable method to collect self-reported needs.

Limitations of the Study

The nature of the population and their present mental status will influence the number of returns. The overriding concern is that those subjects who suffer from affective disorders have a decreased attention span which necessitates that the questionnaire be brief and not necessarily comprehensive.

The sample is not random, as it was sent to all 365 known members of the Society for Depression and Manic-Depression. Only those who completed and returned the survey are included in the analysis.

Only three factors (employment, social support, medications) associated with quality of life were examined. Social support characteristics are not comprehensive and focus exclusively on functional characteristics.

Differing cultural and other social factors may play a role as confounding variables.

The survey framework is not open ended as literature reviews frame the structure of the needs perceived.

These limitations make it difficult to generalize, and will

only give direction for needed further research.

The survey is a 'snapshot' of the community at a particular time. To directly measure changes in attitudes and behaviours, a longitudinal study would be necessary. Time and resources do not allow the investigator to use such an approach at this time.

Overview of the Study

This study was designed to investigate at the community level the relationship between perceived satisfaction and utilization of selected community services and their effect on emotional well being. Involving the consumer directly in the analysis of consumer satisfaction has only recently come to the research forefront. The study as such has a direct application to the consumer movement.

This thesis is organized into five chapters. Chapter One is a brief summary of the nature of the study. Chapter Two presents a review of the related literature. Chapter Three describes the design of the study and the data is analyzed in Chapter Four. Chapter Five gives a summary, the conclusions reached, and finally implications and recommendations for further research.

Definition of Terms

Depression: To meet D.S.M. III-R requirements for a major depressive episode at least five of the following symptoms must be present nearly every day during the same two week period and represent a change from previous functioning; at least one of the symptoms is either (i) depressed mood or (ii) loss of interest or pleasure. The D.S.M. III-R symptoms are:

- i) depressed or irritable mood most of the day;

- ii) markedly diminished interest or pleasure in all, or almost all, activities, most of the day;
- iii) significant weight loss when not dieting or weight gain, or a decrease or increase in appetite;
- iv) insomnia or hypersomnia;
- v) psychomotor agitation;
- vi) fatigue or loss of energy;
- vii) feelings of worthlessness or excessive or inappropriate guilt (which may be delusional) and which is not merely self-reproach or guilt about being sick;
- viii) diminished ability to think or concentrate, or indecisiveness; and
- ix) recurrent thoughts about death (not just fear of dying), recurrent suicidal ideation without a specific plan, or a suicide attempt or specific plan of committing suicide

Manic-Depression: The diagnostic criteria for a Manic Episode is defined as including A, B, and C below. A Hypomanic Syndrome is defined as including A and B but not C, (i.e. no marked impairment in activities of daily living).

- A) A distinct period of abnormality and persistently elevated, or irritable mood.
- B) During the period of mood disturbance, at least three of the following symptoms have persisted and have been present to a significant degree:

- i) inflated self-esteem or grandiosity;
 - ii) decreased need for sleep;
 - iii) more talkative than usual or pressure to keep talking;
 - iv) flight of ideas or subjective experience that thoughts are racing;
 - v) distractibility, i.e. attention too easily drawn to unimportant or irrelevant external stimuli;
 - vi) increase in goal-directed activity (either socially, at work or school, or sexually) or psychomotor agitation;
 - vii) excessive involvement in pleasurable activities which have high potential for painful consequences, (eg. person engages in unrestrained buying sprees, sexual indiscretion or foolish business investments); and
- C) mood disturbance sufficiently severe to cause marked impairment in occupational functioning or in unusual social activities or relationships with others, or to necessitate hospitalization to prevent harm to self or others.

Social Support: Social support is generally defined in terms of: the availability of people in whom the individual trusts, on whom she/he can rely, and who care for and value him/her as a person (Norbeck, Lindsey & Carrieri, 1981).

Cognitive Therapy: Therapy aimed at the beliefs and thought processes presumed to underlie clinical disorder

(eg. self-monitoring; role playing,) (Papolos & Papolos, 1987).

Interpersonal Therapy: Similar to cognitive therapy but emphasizes social bonds and relationships to improve a person's self-concept and communication skills (Papolos & Papolos, 1987).

Chapter 2

Review of Related Literature

This chapter will review the current literature relating to the variables under investigation. Employment will be discussed first, followed by Social Support and finally medications and/or treatment regimes. The latter part of the chapter summarizes those specific aspects under each variable which will be examined by this study.

Society for Depression and Manic-depression

The major mental disorders include schizophrenic and affective disorders. Affective disorders encompass those mental disorders pertaining to mood and affect. The Society for Depression and Manic-Depression of Winnipeg, Manitoba is a community organization designed to help individuals and family members with unipolar (depressive) or bipolar (manic-depressive) affective disorders cope with the myriad problems associated with their disorder. The organization's aim is to "enhance their members ability to cope with the disorder; to develop public awareness of mood disorders, thereby reducing stigma; to advocate for qualified care and improved facilities, adequate staffing and emergency care" (Finnen, 1989). The Society has encouraged this study to directly obtain their members' perspectives on selected issues pertaining to their present coping in the community.

Conceptual Framework

Reviews of the current literature have identified a variety of pertinent issues. Hutchison et al, (1985) in their research on

the community needs of mental health consumers, found several concerns, particularly issues related to employment, housing, the lack of money and the role of self-help groups. Several themes seemed to cut across these categories. For example, the pervasive effects of stigma were significant in terms of employment and housing opportunities. Powerlessness and identity seemed to be crucial issues for former patients as well as hospitalization and the need for friends.

The primary concern for the chronically mentally ill is that of unemployment or underemployment (Kirsh, 1983). Of all the community needs mentioned by people with chronic mental disabilities, employment was the one most noted and most emphatic (Hutchinson et al, 1985). Again and again people expressed the idea that without work or meaningful activity of some kind, day to day living lacks direction and mental health deteriorates. Studies have shown that work is a "critical variable in the way we feel about ourselves" (Matson & Rusch, 1986). Some of the attributes to which work contributes are: "increased self-worth; the making of a valuable contribution; the fostering of pride through doing; increased independence and the comradery of working activities with fellow citizens" (p. 34).

Employment is seen to, potentially at least, provide workers with financial support through income, the basic necessities of life, opportunities for social interaction outside the family, opportunities for self fulfilment, growth and intrinsic pleasure, daily structure, a sense of busy-ness and coherence, a sense of

purpose within a group, a sense of social identity and a contrast from non-work (eg. leisure activities).

However, Matson & Rusch (1986) report that over 80% of former psychiatric patients are unemployed and unemployment has a wide reaching impact on an individual's well being. A recent federal government discussion paper on mental health (Health and Welfare Canada, 1988) pointed out that "there appears to be an association between economic deprivation and increased rates of mental illness" (p. 13) with low income levels as a factor which triggers or worsens the symptoms of mental disorder.

It is widely acknowledged that conditions of poverty create physical risks (Canada Health Survey, 1981) to the extent that poverty and unemployment are strongly related, and that unemployment is a health hazard. Unemployment has been shown to be associated with a range of symptoms including fatigue, weight loss, nervousness, lethargy, diminished attention span, insomnia, and has also been associated with higher rates of bronchitis, ischaemic heart disease and cirrhosis of the liver (Kaplan, 1987). Unemployed people in general, tend to develop irregular sleeping habits, eat less wholesome food but more "junk food" in turn leading to poor nutritional levels, smoke more cigarettes, drink more caffeine, drink more alcohol, and exercise less.

Unemployed persons may lack the economic resources to meet their basic physical needs for clothing, shelter and food. As well, the unemployed person may lose a sense of identity, accomplishment and fulfilment, that sense of self-worth and belonging that many

employed people may take for granted.

Not having employment has been found to be a moderately good predictor of rehospitalization (Kirsh, 1987). Individuals with positive work adjustments are more likely to stay out of hospital and to cope with their problems (Egan, 1976). However, it has been shown that chronic psychiatric patients have higher unemployment rates when compared to non-psychiatric patients.

Several barriers to employment stand in the way: the stigma of mental illness, the effects of some medications, gaps in the individual's work history, lack of work incentives and an entrenched sheltered-workshop mentality of employers (Estroff, 1981). Employers may anticipate the job applicant will "get sick again" or that other employees will feel uncomfortable in dealing with someone labelled "sick".

The chronically mentally ill often have a variety of obstacles to overcome. Not only is a large proportion of this population unskilled in a labour market where demand is for increasingly skilled and specialized workers but often they are handicapped by a lack of job readiness in general and require a variety of services to help them reach the point where they can meet the expectations any employer might have of someone as an employee.

There is a widespread belief that Unemployment Insurance benefits and Social Allowance serve as adequate safety nets for those unemployed. However, the feelings of dependency and inadequacy of living on Social Assistance are extremely evident.

Manitoba provincial Social Assistance recipients at the time of this study receive \$375.00 a month (\$4500.00 a year). As Rioux & Crawford (1990) point out, there are many problems faced by disabled recipients of Social Assistance. For many recipients, the rates of Unemployment Insurance or Social Assistance fall well below the poverty line. They show that benefits are inadequate both in terms of absolute value (their actual levels) and relative value (their value in relation to increases in the cost of living).

Factors influencing the consequences of unemployment include: informal support availability (from kin, friends) and formal support availability (counselling, social services); economic class; relative amount of economic deprivation as a consequence of unemployment; length of unemployment; reality of jobs options available; degree to which the individual wants to be employed and nature of past work experience; skill and educational level; state of health and sense of self-worth (Egan, 1976).

Social Support/Social Networks

Researchers have not been able to definitively conceptualize just what is meant by the term 'social support' nor is there agreement on what specific aspects or dimensions of social support are most strongly associated with well-being. Social support is generally defined in terms of the availability of people whom the individual trusts, on whom s/he can rely, and who make him/her cared for and valued as a person (Norbeck, Lindsey & Carrieri, 1981). Social support may be distinguished from the related concept of social networks, which refers to the roles and ties that link

individuals among aspects of kinship, friendship or acquaintances. Social networks may be seen as the structure through which support is provided (Mitchell & Coppard, 1985).

Persons with any chronic illness are faced with adapting to a variety of tasks. As described by Moos (1981) these include: dealing with the physical symptoms of the illness; managing the required treatment; developing and maintaining relationships with health care professionals; coping with a wide range of emotions; preserving one's self image; maintaining a sense of independence and control while having to be dependent upon others; preserving relationships with family and friends; and living with uncertainty. The availability of social support from a person's social network is one of the major factors that affects an individual's adjustment to a chronic disease (Israel, 1985).

Walker, MacBride & Vachon (1977) define an individual's social network as: "that set of personal contacts through which the individual maintains his social identity and receives emotional support, material aid and services, information and new social contacts" (p. 35).

Israel (1985) describes social networks within a conceptual framework that includes structural, interactional and functional characteristics. The following is derived from a review of her work. Structural characteristics (the links of the overall network) are size or range of the links; and density - - the ratio of existing ties to the number of ties that could exist in the network.

Interactional characteristics refer to the nature of the relationships within the network. Israel has found that the interactional characteristics that seem to be the most important for dealing with a chronic disease are: (1) directedness - the reciprocity/mutuality in a relationship; (2) durability - the stability of network linkages and the degree to which the relationships are changing; (3) intensity - the emotional closeness between network members and (4) dispersion - the ease with which a person can make contact with network members.

Relevant functional characteristics include: (1) the provision of affective, instrumental, and cognitive support; (2) maintenance of social identity; and (3) access to social contacts and social roles. At present, the concept of social support is considered multidimensional, and both functional and network properties are important.

Israel and Rounds (1985) reviewed a number of articles which conceptualize social support within the context of the "buffering hypothesis", that is, that social support buffers or protects the individual from stressful life events. These reviews concluded that social support can interact with life events to produce a positive impact upon physical or psychological well-being.

Comparisons of persons with psychiatric disorders (both psychotic and nonpsychotic) with various normal control populations have found the former to have networks characterized by "fewer linkages overall, fewer intimate relationships, greater asymmetrical and dependent relationships and lower scores on

indices of perceived support" (Mitchell & Trickett, 1980, pp. 36). A comparison of Veteran Affairs (VA) psychiatric patients to VA medical patients, for example, found the psychiatric patients to have fewer intimate ties, less reciprocity in relationships, and a greater unwillingness to utilize their networks in times of crisis (Tolsdorf, 1976). Rehospitalization for schizophrenic patients was found to be more likely if their networks were small, low in density, and lacking in reciprocal relationships (Gottlieb, 1985).

Medication/Treatment Regime

Long term therapy for depression and manic-depression patients is complicated by the fact that medications to control swings in affect, which are an important component of care, often have unpleasant side effects and potentially lethal effects. This constitutes a serious risk for chronic patients on long term maintenance medications. First, the side effects lead patients to discontinue medication, often resulting in a relapse to the previous undesirable behaviours. Second, both problems of patient cooperation and the real dangers of these powerful drugs require close medical supervision and monitoring of these patients. This constitutes a more strategic problem in the community than in hospital, where follow-up is extremely difficult to maintain.

As Diamond (1985) states, medications are prescribed so patients will (1) do well by some objective criterion such as decreased hospital recidivism or decreased symptomology and (2) be as satisfied as possible with themselves and their lives. However,

as he reports, because it is easier to concentrate on the objective criterion, the subjective goals are often minimized.

The issue of having to take medication is of great importance to the patient. The psychological costs imposed by taking medications are a daily reminder that they are chronically mentally ill, that they may relapse again, and that life is nowhere near what they or their families had hoped for or expected. Much of this concern is imposed by the illness itself but for some patients, the daily act of taking medication may be intolerable as it focuses the patient, and his/her family and friends to acknowledge the illness.

Some patients are very upset by the idea that it is not their own will but a medication that is responsible for preserving control over their behaviour, mood or judgment. They may view the lack of psychological control as a weakness. These feelings can lead to a rather negative attitude about the taking of medication.

Medications also are a difficulty for people leaving an institution. They convey "conflicting and confusing messages" to the individual" (Estroff, 1981). Though discharged and certified as "well", the person taking medications and struggling with the subsequent side effects, has brought the hospital experience back to the community. Medication may be a regular reminder to some patients that they are impaired, will never lead a "normal" life, and are controlled by outside factors.

Also, although people talked of the help they receive from medication, others noted it plays a role in devaluing their personal lives. This devaluation occurs because psychoactive drugs

alter the appearance and behaviour of people who then, because they look and feel differently, are treated as different by others. Thus, a person's interpersonal and societal difficulties can actually be increased by use of medication. Many individuals prefer not to take medications for a variety of reasons (side effects, issues of dependency etc.). For these patients alternate treatments have been developed based on the principles of behavioral and cognitive-behavioral therapies. These therapies have been used to help the individual's capacity to cope, to help the person to understand and come to terms with feelings of vulnerability and develop an adaptive way of coping with interpersonal problems that emerge or are magnified by the illness (Papolos & Papolos, 1987).

Two short term theories designed specifically for depression are cognitive and interpersonal psychotherapy (Papolos & Papolos, 1987). A study funded by the National Institute of Mental Health (1985) concluded that cognitive therapy and interpersonal therapy were as effective as imiprimine (a tricyclic antidepressant) in reducing the symptoms of depression and improving the functioning of patients (Leo, 1986). However, there were no criteria or definition of just what constituted "functioning".

Whether these specific psychotherapies or others also play an adjunctive role with pharmacotherapy in preventing recurrence has not been firmly established. Based on the present state of knowledge, for nearly all patients suffering from major recurrent mood disorders, psychotherapy should be used in combination with, and not as a substitute for, pharmacotherapy for long-term

preventive treatment (N.I.M.H., 1985).

Summary

While realizing there are a number of pertinent areas which need to be addressed for those chronically mentally ill living in the community, research and monetary constraints dictated that only a few selected issues derived from the literature would predominate.

The literature review clearly implicates employment as an issue impacting on the individual's well-being. Time and resources however, require that the study limit its analysis to only certain aspects of the employment issue, particularly those issues linked to the service component of employment. Thus the study undertook to analyze the issues of the barriers to employment, perceived availability of employment and how these affected the individual's feelings of independence.

The literature review also examined the structural, interactional and functional characteristics of social support. Israel (1985) states that agreement does not exist regarding what specific aspects or dimensions of social support are most strongly associated with well being. This study took the liberty of focusing on only the functional characteristics (feedback; informational support; instrumental support) as they are tangible variables and most clearly recognized or tied in with the provision of services.

Side effects and feelings of dependency were the issues studied in relation to medications. The determination of the psychological costs of taking medication is rarely acknowledged or

examined by health professionals yet the chronically mentally ill continue to voice frustration with the perceived indifference regarding their treatment regimes.

These selected aspects of employment, the influence of social supports and the implications of medications on self-esteem, viewed as the investigative variables, were correlated to the variables of mood or affect symptomology as defined by the D.S.M. III-R.

A baseline of perceived satisfaction with community services and how their utilization is reflected in the individual's symptomology was developed. Subsequently, the study will be utilized to prepare possible recommendations to policy changes and to guide future research on community needs for the chronically mentally ill.

Chapter 3

Design and Procedures of the Study

This chapter is concerned with procedures used to gather the research data. The development of the test instrument is described first, followed by a description of the pilot studies. The latter part of the chapter is devoted to describing the research sample.

The research instrument was designed to assess four main components: the variables of satisfaction with employment, social support, and medication regime, and their relationship to mood.

In July 1991, the research instrument developed by the investigator was mailed to the members of the Society for Depression and Manic-Depression. Scores were obtained for each component variable and examined for correlations.

Operational Variables

Established instruments (Beck, 1977; Dupuy, 1977; Goldberg, 1972) to assess depression/manic-depression are generally quite lengthy and given the restrictions of a mail survey, it was decided to institute an abbreviated set of questions to encompass diagnostic criteria for an individual's affect. An abbreviated form was constructed based on the diagnostic criteria of the Diagnostic and Statistical Manual of Mental Disorders (third edition - revised). Questions (see Appendix A) were based on symptoms required to meet the diagnostic requirements for that particular mental disorder.

The diagnostic criteria include subjective feelings of depression/excitement, taking interest in daily activities, sleep

patterns, feelings of fatigue, concerns for the future, thought perseveration, and finally, emotional state. These variables are not exhaustive of the criteria for depression/manic-depression but were selected to be indicative of the individual's affect for the two weeks prior to the study.

The variables of social support, employment, and medication regime were selected in part from literature reviews and from identified concerns from the Society for Depression and Manic-Depression.

A five-item Likert scale taken from Weissman's (1977) self-report Social Adjustment Scale was employed to measure respondents' perceptions to their satisfaction with social support. The instrument focused on the functional characteristics or those variables most clearly recognized with the provision of services. Questions covered the two weeks prior to receiving the survey and focused on the level of social contacts, levels of independence and satisfaction with perceived availability of social support. Five and six point response scales were used, with lower scores representing increased impairment.

An eight-item Likert scale to measure respondents' perceptions to satisfaction with employment also incorporated several questions from the Social Adjustment Scale (Weissman, 1977). Two- and five-point response scales were used, with lower scores representing increased impairment.

No suitable rating scale or questionnaire was located for dealing with an individual's satisfaction with his/her present

medication regime. Medication questions were developed from Diamond's (1985) research and employed a three- and four- point response scale. As with the other independent variables, lower scores represented increased impairment or dissatisfaction.

Research Instrument

The instrument was a mailed survey consisting of a combination of open and closed questions. The advantages and disadvantages of closed versus open questions in a mailed survey are comprehensively discussed by Dillman (1978). Some of the attributes outlined by Dillman used to try to increase response rate were: through announcements at the Society's chapter meetings, advance notice was given that a survey would be conducted; inclusion of stamped pre-addressed return envelopes with the survey; official sponsorship of the survey by the Society; and respondent anonymity. Although closed questions demand that people select from offered alternatives rather than giving their own responses, their specificity reduces risk of misinterpretation (Converse & Presser, 1989). Offered responses to closed ended questions, providing they have been appropriately structured, can elicit significant differences among respondents (Dillman, 1978). Open questions are preferred when lack of information prevents the writing of appropriate response categories or when exploring sensitive areas of behaviour (Converse & Presser, 1989). Given the nature of the population sample and the potential for decreased motivation and/or concentration, open ended questions were kept to a minimum.

The study utilized a cross-sectional design. The cross-

sectional design is the most appropriate tool to measure a wide number of variables for different age groups at the same time (Converse & Presser, 1989)

Pilot Tests

The research instrument was submitted to two trained professionals, one, a practising psychiatrist and the other, a unit manager of a small psychiatric unit, both individuals possessing substantive knowledge of the survey topic. Two pilot tests were then conducted, one using volunteer members of the Society for Depression and Manic-Depression and another using the in-patients of a small psychiatric unit.

In the first pilot study, seven volunteers from the Society for Depression and Manic Depression evaluated the research instrument. Questionnaires were handed to these individuals and their criticisms and suggestions were solicited. The initial pilot test was used to determine the appropriateness of the questionnaire and its relevance to the individual.

The second pilot test was conducted with three patients on a nine-person psychiatric ward. This pilot test was used to determine question comfort, the ability to understand the meaning of the questions and the time needed to complete the questionnaire.

The pilot tests were useful in establishing that the time of fifteen minutes allocated for the survey was realistic. It also enabled the investigator to clarify the objective of each question based on responses and comments from the group. Questions deemed to be redundant were eliminated from the questionnaire and several

others, specifically those pertaining to mood, were included. A standardized format was developed and readied to be sent out by mail.

Sample

The sample consisted of three hundred and sixty five individuals determined by the Society of Depression and Manic-Depression's listings of the names and addresses of individuals who are Society members. Usable questionnaires were received from 143 respondents.

Demographically, the sample consisted of 87 females and 56 males, ranging from 21 to 80 years of age. Those living outside the greater Winnipeg city were distinguished from those residing in Winnipeg. As the sample was limited to the membership of a self-help group, random sampling was not achieved and thus may not represent the population as a whole.

Testing Procedures

Early in July 1991, each survey was mailed out accompanied by a covering letter and a return envelope addressed to the Society for Depression and Manic-Depression. A second follow up letter was sent out two weeks later to those individuals who had not yet responded. A third letter, as recommended by Dillman (1978), was constructed but not sent due to monetary constraints. Informed consent was presented in the covering letter. Respondents were informed that participation in the survey was strictly voluntary and that all individual information would be held confidentially.

Statistical Analysis

There were several statistical techniques applied to the data. Kendall tau-b correlations were used to determine the relationship between the dependent variable and the independent variables in hypotheses 1 to 3. The Kendall tau examines the association between ordinal variables and determines the strength of the association. Kendall tau-b is a measure of the association between ordinal variables that takes into account the number of tied pairs. The null hypothesis is that the variables are not associated.

The Kruskal-Wallis test was used to determine the relationship between subgroupings of mood and age, gender, and location. Kruskal-Wallis, a variation of the Mann-Whitney test, is a procedure that can be used to compare ordinal measures in order to detect differences among variables. The null hypothesis is that the population subgroups are identical. Age was broken down into three categories: old (those born before 1931); middle aged (those born in and after 1931 before 1961) and young (those born in and after 1961). Gender breakdown is self explanatory and location was divided into Winnipeg and Outside Winnipeg.

All statistical analyses were conducted at the 0.05 level of significance. This reflects that the chance of rejecting the null hypothesis when it is true as less than five in a hundred as well as accepting a small risk of failing to reject the null hypothesis when it is false. It is a compromise between too little proof and too much proof and is almost universally used as the cut-off point (Hassard, 1991).

Chapter 4

Analyses of the Data

The main purpose of this study was to collect empirical data to investigate how individuals suffering from depression and manic-depression were coping in the community. Coping was determined by focusing on four major components: affect (mood), employment, social support and medications. The effects of age, sex and location were also examined for any correlations with affect.

Data obtained in this investigation were processed through the University of Manitoba Computer Centre.

The initial phase involved a descriptive analysis of the data, including the arrangement of scores into frequency distributions, the means and medians of each component, and a survey of the dispersion of scores within each component with examination of the range, standard deviation and measures of variance.

In the second phase of the analysis, the scores on the components were correlated in order to discover the relationships between: 1) mood and social support; 2) mood and employment and 3) mood and medication regime using Kendall's tau b. Mood was subsequently broken down into three categories: depressed, stable and manic to determine if any correlations existed between subgroups of mood and any of the independent variables.

Age, sex and location were examined to see if there was a significant influence on mood or affect utilizing the Kruskal-

Wallis test. For all statistical analyses , the .05 level of significance was used.

Descriptive Analysis of the Data

Subjects

Three hundred and sixty-five surveys were sent by mail and 151 surveys were returned. The final total of usable surveys was 143. The rough response rate was 143/365 or 39.2 %. It was difficult to determine which of the original 365 who were not eligible and who were not reached, to effectively determine a true response rate. Difficulties existed in determining whether those who responded differed greatly from those who did not respond. "At the level of a fifty percent response rate, extreme distributions from refusals are capable of affecting observed distribution by as many as 50 percentage points." (Dillman, 1977). This leaves the possibility that no matter how close the distributions for the variables being considered, large differences may exist for responses to the questions most central to the objectives of the survey.

Non-usable returns

Eight returns were not used in the final tabulation. Five of the surveys had their title pages removed when they were returned, thus the demographic data and the first six questions were not available for analysis. Two surveys indicated that they had been filled out by someone other than the member to whom it was addressed and thus were not included. One return came in almost five months after the survey first went out and was

excluded.

Factors affecting response rate

People on the mailing list were not necessarily sufferers themselves. Individuals may be on the Society's mailing list to obtain information about the disorder for friends and relatives. Valid returns were only accepted from the individual sufferers themselves.

One must assume that due to the nature of the population some respondents were hospitalized or were too ill to respond.

The survey was done in the summer when many families are on vacation. The survey did, however, allow for a response time of six weeks from the date of the first mail-out.

One must take into consideration that people may have moved and had not notified the Society of their change of residence. Lastly, clerical errors on behalf of the Society in transcribing the mailing list also must be considered.

Factors affecting response

Interest in the particular topic, a factor that seems likely to affect one's answers, may be important in determining whether a questionnaire is completed and returned. It was assumed that the individual was concerned and committed to filling out the questionnaire.

A second factor likely to contribute to questionnaire response is the ability to provide written answers to a questionnaire. Given the nature of the population, open-ended questions that required considerable expansion or concentrated

thought were kept to a minimum. With open-ended questions, people find it more difficult to express themselves in writing than orally. People who have less education are more likely to be intimidated by open ended questions and are likely to be underrepresented among those who responded. Older persons also seem likely to be underrepresented, partly because of lower educational attainment, but also because of more difficulties with their seeing and writing capabilities.

The absence of an interviewer did not allow probes to elicit expanded responses therefore some answers are difficult to interpret or for some responses there are no answers at all.

One source of inaccuracy may be a tendency to offer socially desirable answers, that is to answer questions in a way that conforms to dominant belief patterns among groups to which the respondent feels some allegiance or identification (Lord, Schnair & Hutchison, 1987). In general, respondents have been found to be consistently honest in a mail survey (Dillman, 1978).

One must be aware of contamination by others, that is, having the individual asking advice from others while answering the questionnaire. Unfortunately, the researcher can never be sure under what conditions the mail questionnaire was completed, thus the possibility of contamination becomes a constant concern.

Survey Results

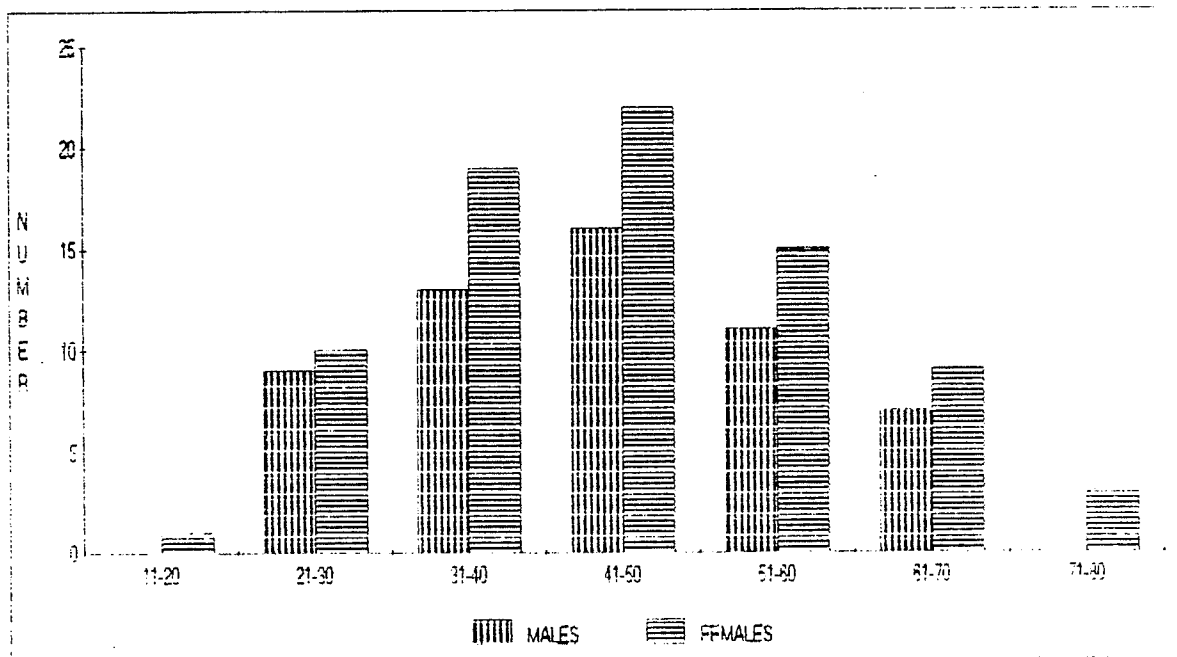
The survey was divided into five sections comprising demographic data, information on mood and the variables of employment, social support and medications. Information was

elicited about the degree of satisfaction/dissatisfaction or present coping abilities with each component.

Demographics

The population sample consisted of 83 females and 56 males. Two individuals did not disclose their sex. The sample ranged in age from 19 years to 80 years. The range for females was from 19 years of age to 80 years and the range for males was from 22 years of age to 69 years. The median age for the males was 45 years, the median age for the females was 46 years. Eight returns did not report their ages.

FIGURE 1. FREQUENCY DISTRIBUTION OF SUBJECT AGE RANGE IN YEARS



Research variables

Four scores were generated for each individual based on their responses to the respective variables of mood, social support, employment and medications. Each variable consisted of

between four and eight questions. For each variable, a sum total score was computed. This score identified the degree of impairment or satisfaction as reported by the individual along a continuum.

TABLE 1. MEANS, STANDARD DEVIATIONS AND MEDIANS OF VARIABLES

Variable	N	Mean	Standard Deviation	Median
Σ Mood Score	140	24.24	4.33	24.00
Σ Social Support	140	19.45	3.85	19.00
Σ Income	86	20.56	3.61	20.00
Σ Medication	131	8.22	1.95	8.00

Mood/Affect

Individual scores for mood were determined from summing the first eight questions on the survey. For computing mood scores, responses were scaled 5-1. This was done to ensure that the first responses to a question reflected manic symptomology and that latter responses corresponded to depressive symptomology. Questions 4,5, and 8 were given reverse scoring (See Appendix A). Thus, instead of responses being scored 5-1 for these three questions, responses were scored in reverse to give a score of 1-5.

This summed score identified along a continuum, the degree of impairment in affect as reported by the individual. Mood

questions were designed such that the first couple of responses to a question reflected manic symptomology. The middle responses tended to be indicative of someone who was stable. The latter responses corresponded to depressive symptomology.

Scoring each question on a scale of 5-1 and adding the 8 mood questions resulted in a total mood score. If the first two responses were suggestive of mania, a cut off score should be in the range of 32. For the depressive individual, the latter responses should have resulted in a cutoff score in the area of 16. Scores between these two figures were therefore judged to be indicative of someone categorized as stable.

The lowest possible score was 8 with the highest score possible being 40. A score of less than 19 was judged to indicate an individual's self assessment as "depressed". Scores between 19 and 31 classified an individual as "stable". A score greater than 31 categorized someone as "manic". The range of scores for mood varied between 16 and 34, with a mean of 24.2 and a standard deviation of 4.33.

Ten individuals were classified as "depressed"; 121 individuals categorized as "stable"; and 12 individuals judged to be "manic". The use of personal interviews would likely have resulted in increased numbers in the categories of manic and depressed. Given the nature of those individuals who would fit these categories, it is likely that nonrespondents would have been too ill to respond.

Employing the Kruskal-Wallis test, utilizing these

classifications to examine correlations with mood and location, sex and age, resulted in no correlations showing statistical significance. The lack of statistical significance may be due to the low numbers of respondents categorized as manic or depressed. Literature reviews do, however, tend to corroborate that there is little or no differences between rural/urban; male/female or between age groups and how they influence the degree of impairment of mood disorders (Moss, 1989, Hartman, 1988).

Employment

Employment examined the issues of employment, unemployment, and part-time work, the barriers to locating and securing employment, and finally the ability to obtain sufficient income to meet an individual's activities of daily living.

An individual's score of satisfaction with employment was generated by summing each individual's responses to the employment questions (questions 10 -22). Questions were designed so that the last or the latter responses would be indicative of decreased satisfaction. Responses were scored in descending order, 5-1. Scores were based on presence or absence of symptoms. Values greater than 27 were determined to be positively associated with employment satisfaction due to the wording of the question. Values less than or equal to 27 were assumed to be negatively associated with employment satisfaction. Scores ranged from 16 to 30 with a mean of 20.5 and a standard deviation of 3.61. Values had a potential range from 8 to 31.

The examination of the correlation of total affect scores

with the three other variables resulted in nonsignificant statistical correlations. Breakdown by subgroupings of affect and correlating with the other variables did result in significant correlations but only for the stable population. There was no apparent pattern visible for those categorized as manic or depressed. The survey was unable to pinpoint for statistical purposes, adequate numbers of individuals who could be classified as manic or depressed. It is realized that these categories were artificially derived and necessitate further corroboration to confirm or reject these categorizations. It is speculated that those classified as manic would exhibit high satisfaction correlations and that those classified as depressed would exhibit low satisfaction correlations. Further investigation should be carried out to corroborate this hypothesis.

Table 2 represents the Kendall tau b correlation between mood scores for those judged to be stable and total employment scores.

Table 2. Correlation Between Stable Mood and Employment

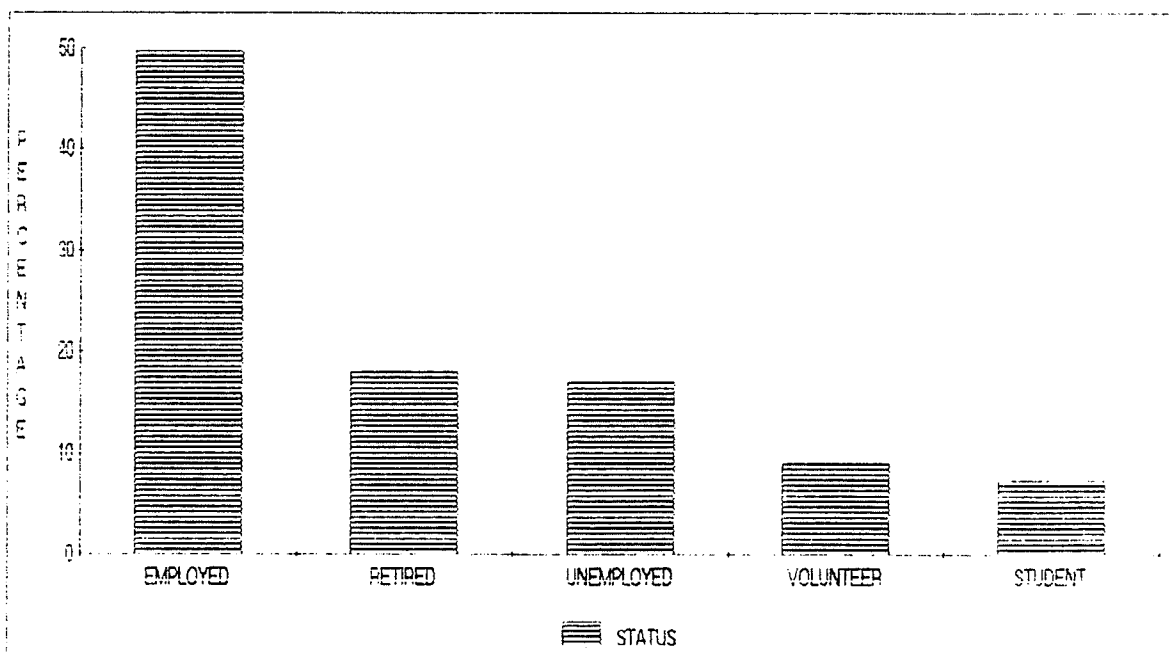
Sample	Degrees of freedom	r	Significance
85	84	.32	.01

Hypothesis 1 states that there is a significant correlation between perceived satisfaction with employment and low scores of depression and manic-depression as defined by the Diagnostic and Statistical Manual of Mental Disorders (third edition -

revised). The analysis of the mood and employment scores using the Kendall tau b correlations indicates that there is a significant correlation between mood scores for those categorized as stable and employment scores. The correlation is significant at the 0.01 level. Hypothesis 1 of a significant correlation between perceived satisfaction with employment and mood stability is thus accepted.

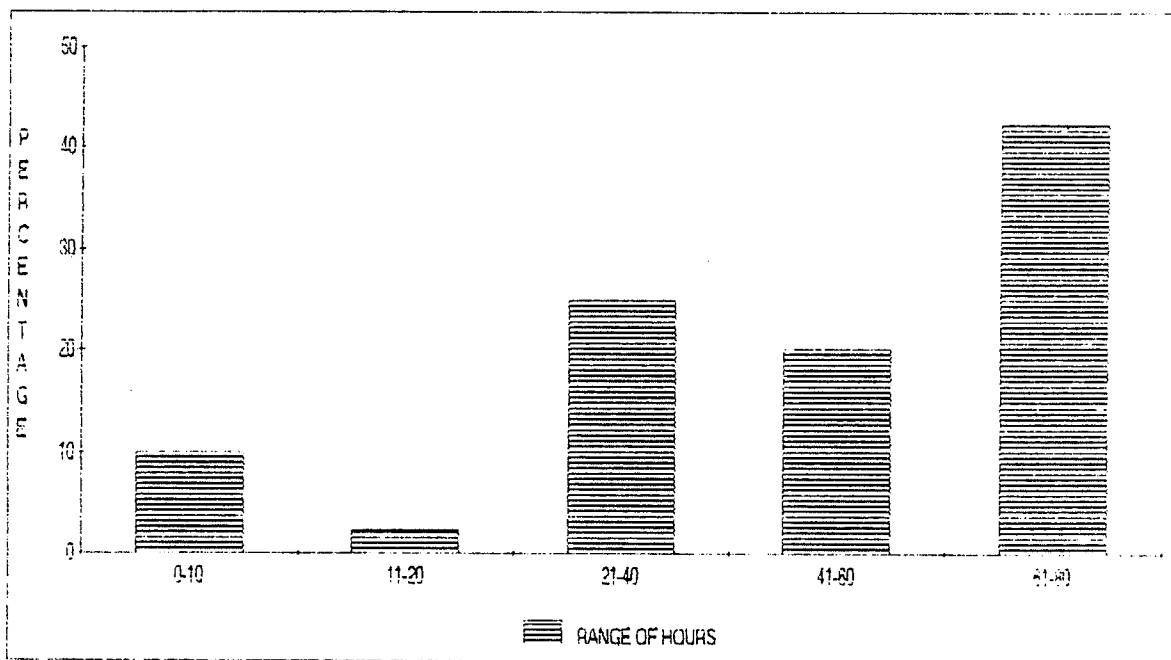
A further issue analyzed under the issue of employment was the difficulty that the mentally ill encounter in locating and holding on to employment. Sufferers from mental illnesses experience substantial impediments to finding and keeping a job. While a significant proportion of those with mental disorders are employed, sufferers are much less likely to be working than their non-disabled peers (Hayes & Hartman, 1990)

Figure 2. Occupational Breakdown



While 49.7 % of respondents indicated that they were employed, only 42.2% of the employed respondents were able to locate full-time employment (see Figure 3). Those who were able to find part-time employment (57.8%), were working a range of hours from less than 10 hours in a two week period ranging to 60 hours. In stark contrast, National figures as reported from Statistics Canada (1990), indicate that in 1989, 17% of all employed people worked part-time.

Figure 3. Hours worked in Previous Two Weeks



While not all of the respondents were dissatisfied with their part-time employment, many of the respondents expressed displeasure at not being able to find full-time work. Sixty-two percent of respondents indicated that they were working as many hours as they would like, while 37% indicated dissatisfaction

with the number of hours they had been able to work.

A variety of issues arose surrounding inability to find work. For those desiring increased employment, identified barriers included: dysthymic mood, perceived lack of employment opportunities, "fuzzy thinking" and increased mood swings.

Just over half of the respondents felt that their illness influenced their ability to find and keep a job. The most frequently cited impediment was having to terminate their job due to suffering either bouts of depression or mania. The second most cited restraint was the employer's attitude towards the individuals' illness. Several respondents spoke of hiding their illness from their employer. "My boss didn't understand my taking time off from work to make a doctor's appointment." "Who would hire someone with a mental disorder." Being honest about their illness had left many with the perception that their illness was a negative factor and often prevented their being hired.

Several spoke of an inability to concentrate and having to transfer to less demanding work. A decreased feeling of energy or motivation resulted in numerous respondents being unable to hold onto their present jobs. "I have no confidence in my abilities when I'm feeling depressed." "The blow to my self-esteem resulted in re-training and re-employment in a job at one-third of my former wages." As Matson and Rusch (1986) point out this is a common phenomenon where the mentally-ill encounter a cyclical association between worsening symptoms of mental disorder and decreasingly low income levels.

When asked what would most benefit the individual in finding and holding onto a job, an ability to achieve stable moods was the most prominent response. An expressed need for improved drug therapy to control mood swings and job counselling skills, including ways to increase self-esteem, were prominently highlighted. Understanding or empathetic employers who would provide time off when needed was also cited as well as a variety of suitable employment tailored to the needs of the mentally ill. " What I need is a leave of absence, so I don't have to quit and start the whole job seeking process all over again."

The elimination of the stigma of the disease and understanding from co-workers also would help individuals to feel they are valued and contribute to the working environment.

Sixty-four percent of respondents reported that they had sufficient money to meet their needs but 54.9% reported they had insufficient income to participate in leisure activities. This bears further investigation. What is the relationship between money for basic needs and money for leisure pursuits? What is the median income level for this group? Does it allow for any disposable income?

Winnipeg's present rate of unemployment is 10.4% (Graham, 1992) while 17 % of the survey respondents indicated that they were unemployed. This discrepancy can be better understood by the fact that a far higher proportion of the mentally-ill are not in the labour force at all; that is, they are neither employed nor looking for work. Their illness prevents them from taking the

necessary steps to commence searching for employment.

The psychiatrically disabled continue to be stigmatized by employers and the community; jobs are doubly difficult to obtain for groups who historically have been unemployed and are perceived to be unemployable.

Social support

Social support looked at the attributes of functional support, those issues most clearly tied in with provision of services. An individual social support scale was devised by generating a score for each individual based on the summation of the five component questionnaire scores. The first two responses to each question were formulated to be indicative of high social support. Social support scores ranged from 11 to 27 with a mean of 19.4 and a standard deviation of 3.85. Scores greater than or equal to 21 were judged to have high social support. Scores less than 21 were regarded as having low social support.

Table 3 represents the Kendall tau b correlations between mood scores for those judged to be stable and total social support scores.

Table 3. Correlation Between Mood and Social Support

Sample	Degrees of Freedom	r	Significance
138	137	.46	.01

Hypothesis 2 states that there is a significant correlation between levels of social support and decreased signs and symptoms

of depression and manic-depression as defined by the Diagnostic and Statistical Manual of Mental Disorders (third edition - revised). The analysis of the mood and social support scores using the Kendall tau b correlation indicates that there is a significant correlation between mood scores for those judged to be stable and social support scores. The correlation is significant at the 0.01 level. Hypothesis 2 of a significant correlation between satisfaction between levels of social support and mood stability is thus accepted.

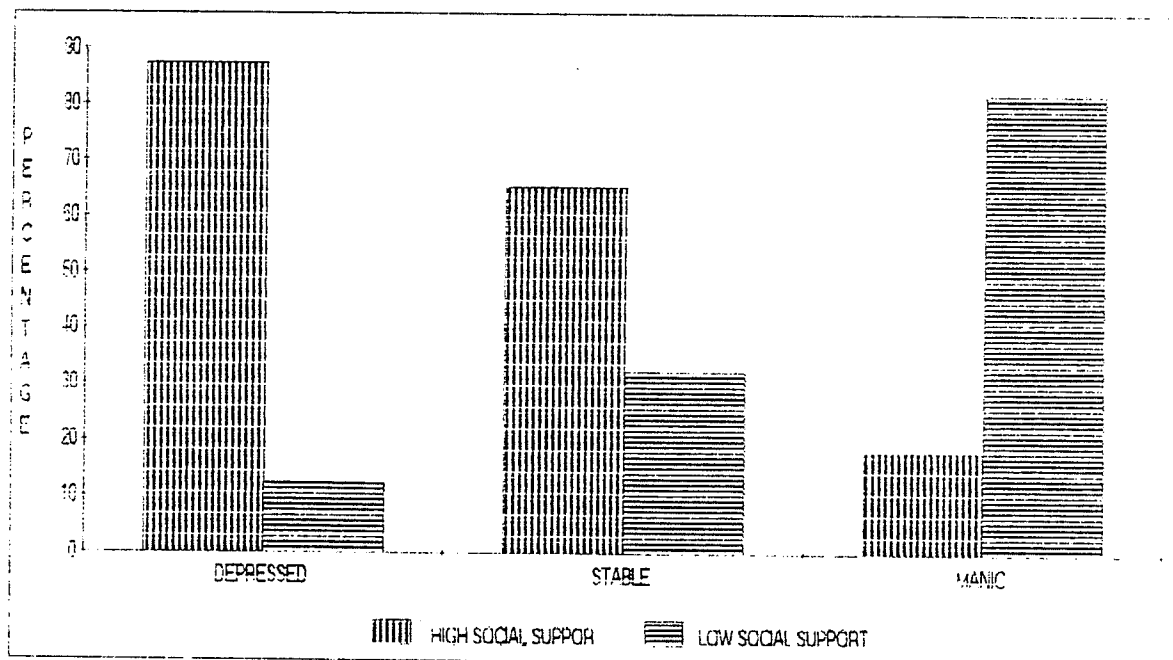
One-third of respondents named the Society for Depression and Manic-Depression as relevant and helpful in helping to cope with their disease. The next highest response was the individual's religious institution, followed by involvement with community services (Parks and Recreation, Y.M.C.A.). A significant number found assistance through an educational approach either through a Community Nurse or through the Public Library.

As Crosby (1987) observes, families of seriously ill persons have a great need to learn to know what they are up against. Not surprisingly, the literature, lectures and services of the Society were the most appreciated. Self-help groups provide an invaluable service to sufferers of a chronic disease. Being in contact with others with similar problems is a healthy adaptive response. In others they find a "validation of their experience, sources of information and role models for coping behaviour" (Gottlieb & Coppard, 1987).

Respondents often included feedback on choices of additional help they would like to see covered by the Society. They would like to see increased education and information on knowledge and understanding of patient's symptoms; easier and enlarged access to professional help; specific suggestions for coping with patients' behaviours; people to talk to who have undergone a similar experience; more understanding from friends and relatives and increased therapy for the individual. The importance of knowledge, information, and social support for families in this stressful situation is clear.

Figure 4 compares subgroupings of mood and examines the relationship to perceived social support.

FIGURE 4. AFFECT VS. SOCIAL SUPPORT



An interesting occurrence can be seen for those who are

judged to be depressed. A very high proportion of those classified as depressed show a significant score for high social support, in contrast to those considered to be "stable" or "manic". At this stage one can only speculate as to why the difference exists among the groups. Manic behaviour is impulsive and frequently irrational, having a tendency to alienate friends or family, thus discouraging social contacts. Depressive behaviour usually results in an individual withdrawing from the social world. Depressive behaviour may be seen as less unpredictable and more socially "acceptable" than manic behaviour. Family members may be more apt to interact and assume that attention and assistance will restore a depressive person's capacity to respond. Many family members offer this kind of help and provide what is required by the situation.

It appears that one's social network has a great influence on a person in it. This influence can either inhibit or encourage utilization of services, depending on the relationship among the person, his/her network, the immediate environment and specific symptoms the person has (Gottlieb, 1988). A tightly knit network can either discourage or encourage an individual from seeking help, depending on how the individual's behaviour or symptoms are perceived by the group.

Medications

Medications looked at the issues of side effects, the degree of control that medications exerted in the individual's life and alternative therapies. Satisfaction with medications was based

upon summing of the four pertinent questions and deriving categories of satisfied and dissatisfied individuals. Questions were formulated so that the first two responses were suggestive of medication satisfaction. The lowest possible score was 4 and the highest possible score was 15. Scores of 11 or more were judged to be indicative of satisfaction with present medications. Scores of ten or less were categorized to be representative of dissatisfaction.

Table 4 illustrates the Kendall tau b correlations between mood scores of those classified as stable and total medication scores.

Table 4. Correlation Between Mood and Satisfaction with Medications

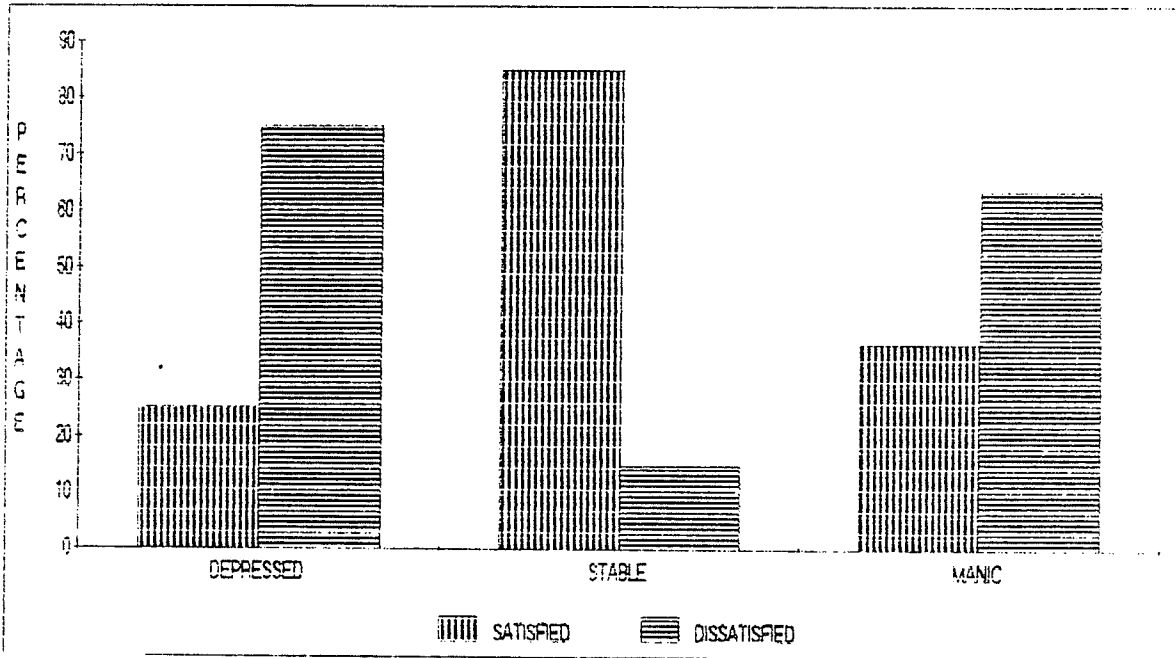
Sample	Degrees of Freedom	r	Significance
128	127	.22	.01

Hypothesis 3 states that there is a significant correlation between satisfaction with medications and/or treatment plans and decreased signs and symptoms of depression and manic-depression as defined by the Diagnostic and Statistical Manual of Mental Disorders (third edition - revised). The analysis of the stable mood and medication scores using the Kendall tau b correlation indicates that there is a significant correlation. The correlation is significant at the 0.01 level. Hypothesis 3 of a significant correlation between satisfaction with medications and

mood stability is thus accepted.

Figure 5 illustrates the relationship between affect and satisfaction with medications.

Figure 5. Satisfaction with Medications



It is logical to expect that those individuals who recognize they are in either a manic or depressed phase would express some dissatisfaction with their medication regime. Seventy five percent of those designated as depressed expressed dissatisfaction with their medications, while 63.6 % of those categorized as manic indicated their dissatisfaction with their present medications. For those who were rated as "stable", 85.1 % indicated satisfaction with their present medications.

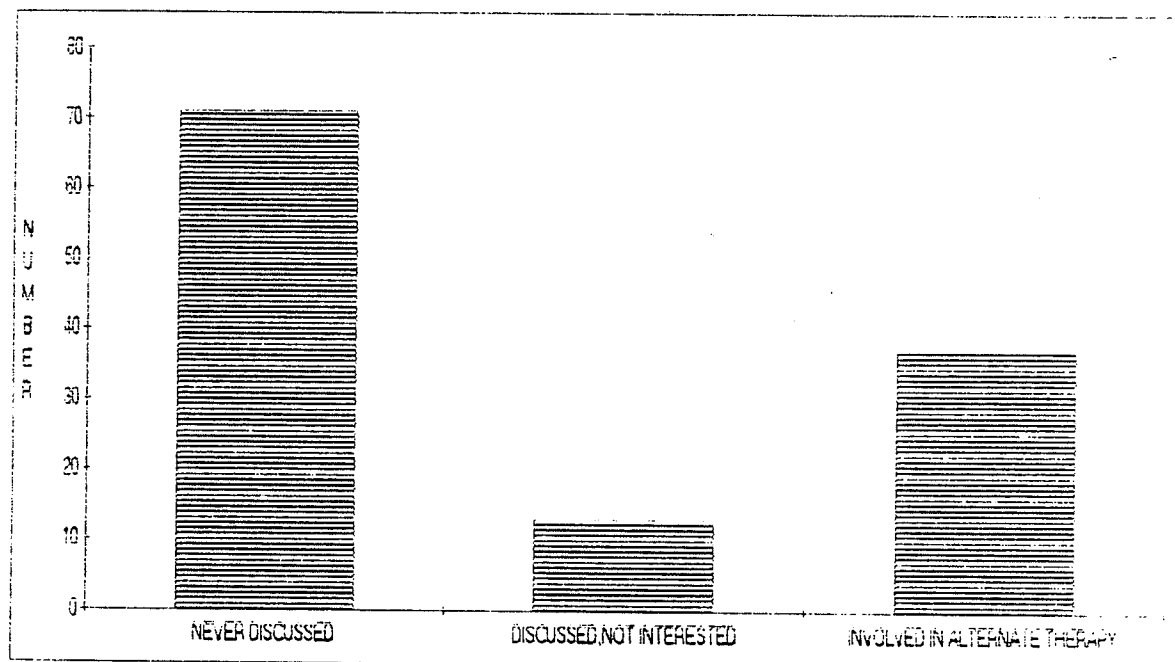
Utilizing all of the respondents, 50 % indicated that their medications did not cause them any perceivable side effects. Only 16.5 % reported side effects severe enough to interfere with

their activities of daily living.

Question 32 asked respondents to declare their perceptions as to whether medications ran or controlled their lives. Forty-six out of 133 respondents (34.5%) indicated that they felt that their medications and not themselves exercised the control in their lives. While many patients would like to wean themselves from the daily ritual of having to take medications to control their mood swings, at present, for the vast majority of patients, medications are the most viable route to maintain control.

Alternatives to medications were explored with respondents. Almost 60 % of those questioned indicated they had never discussed medication alternatives with their physician. Eleven percent (see figure 6) were at least aware of alternatives such as cognitive therapy but indicated they were not interested in pursuing any alternatives at this time. Approximately one-third were informed as to alternatives and were currently involved in some alternate therapy in addition to medications.

Figure 6. Awareness of Alternatives to Medications



Patients need to be fully cognizant of all their options to optimize their treatment. Consumers need to be told there are alternatives or adjuncts to medications. What is optimal for one patient is not necessarily optimal for another. Only by giving the individual the opportunity to explore a variety of treatment modalities can a patient make an informed choice as to which programs meet his/her specific needs.

Summary

This convenience sample was selected from the mailing list of the Society for Depression and Manic-Depression. It was therefore a biased sample and not representative of the total needs of the community for mental disorder care. This is the first use of these scales in this form, which requires

replication with a larger and more representative sample to determine reliability and validity. However there is some indication of construct validity in the scales because of the significant correlations obtained.

A correlational study was conducted with over 140 clients of a community self-help group for mood disorders. For these mental health consumers, relative significant correlations were found between mood and the independent variables.

All independent variables showed significant correlations with mood. A strong correlation (.46) was shown between mood and social support. Employment and medications also demonstrated significant correlations but to a lesser degree.

Medication questions tended to examine predominately the negative aspects of taking medications. With 85.1 % indicating satisfaction with their medications, it is not surprising that such low correlations predominated.

Employment issues examined satisfaction with employment, obstacles to finding and keeping work and earning sufficient income to meet their daily needs. Less than 50 % of the respondents indicated they were employed with only 42.2 % of that percentage were working full time. Given the nature of the population under study, it was expected that there would be a significant number of individuals not employed, and the survey bore this out. What is surprising is the number of individuals who were satisfied with their limited hours of part-time employment. Further investigation should examine the role of

part-time employment (hours worked, income earned, educational levels, job classification etc.) and the individuals quality of life.

This survey's conceptualization of social support looked only at the functional characteristics. Further studies should examine the structural and interactional characteristics of social support as well, to determine their role in maintaining mood stability. As Egan (1988) points out, through both informal (kin and friends) and formal (counselling and social services) support availability influences the consequences of unemployment. There was a significant correlation (.34) between social support and employment. This issue should be examined in depth for a later study.

A major problem with investigating social support, however, is the variety of definition and ways of operationalizing of the concept itself. To date, conceptualizations of social support have been given such wide scope that their usefulness are suspect. Without clear and concise conceptualizations, there will always be mixed results for the attempts to link social support and any preventive or curative effects that it may have for the individual.

Chapter 5

SUMMARY, CONCLUSIONS AND IMPLICATIONS

This thesis represents the results of an exploratory study of the relationship between conceptualizations of mood and the experiences of employment and social support and the use of medications. The constitution of the sample, the development of the questionnaire and the collection of the data were all designed for efficiency and economy. It was hoped that such information could be used to explore the relationship between mood and client satisfaction with employment, social support and mediation use. It also was hoped that this work could lead to insights into the individual living in the community's mood and could lead to development or improvement in services provided to consumers of mental health.

Suggestions for Further Research

- 1) One suggestion for further research would be to replicate the study, sampling other populations to see if the findings of this study would agree with the findings on other mood disorder groups and on more heterogenous populations.
- 2) It would be useful to determine, for the purpose of this study, whether the scales used to determine affect, satisfaction with employment, satisfaction with social support, and satisfaction with medication therapy would measure these variables on a different population and whether some concurrent validities could be established for these scales.
- 3) Because this is a relatively small and biased sample, the

survey should be administered to a larger and more broadly representative group of sufferers from depression and manic-depression. A listing of those who have been opened up to Community Mental Health might elicit a more broadly representative group of participants. This population would provide a better idea of the extent of the need for services in the community.

4) This study did find significant correlations between the dependent variable of mood and the independent variables of employment, social support, and medications. It might be worthwhile to examine in more depth the interrelationships among mood and other social factors.

5) The methodology of the study could be modified so as to incorporate further validating content. For example, differences in education might be significant. Further, due to the nature of the population, few respondents who met the criteria of depressive or manic were able to participate in the survey. Personal interviews would help to include this portion of the population. Finally, it would have been helpful if the survey had been less general and more specific, focusing on just one independent variable.

6) It is possible that the homogenous group selected for this study did not display the full range of affect expected of a random sample, which could cause the correlations to be spuriously low. It also is possible that the scales in either a newly created form or in an abbreviated state were not valid measurements of their specific constructs as used by other investigators. These factors must be taken into consideration in any future study.

7) Psychotropic medication plays a powerful role in the community treatment of the chronic mood disorder patient. There are, however, a number of important psychopharmacological questions to be answered. These include differentiating between patients who need maintenance therapy and those who do not; learning more about dosage levels required for maintenance; and learning about compliance.

Summary

The deinstitutionalization and community health movements have led to a large increase in community treatment programs for the chronic psychiatric patient, yet there has been little research evaluating their efficacy. This thesis reviews some of the studies examining certain aspects of programs necessary for the individual suffering from a chronic mood disorder to exist and thrive while living in the community.

Findings of this study show that for patients judged to be stable, there is a significant correlation between their mood and satisfaction with employment, social support and medications. There was insufficient data to correlate findings for patients judged to be either depressive or manic-depressive.

Suggestions were given to improve existing gaps in services. Improved services were identified as being insufficient without maintaining some form of sustained community commitment to these programs.

Much work remains to be done in isolating the critical variables in community treatment programs in order that they may be

implemented in the most streamlined form.

The major need in standardizing research in community treatment is the development of a sensitive instrument to measure community adjustment. Some aspects such as employment and living arrangements are relatively straight forward to measure. However, daily living skills, social activity, social relationships, quality of life, and satisfaction with life are vital aspects of community adjustment that are difficult to measure. The instruments presently available leave much to be desired and the development of a community adjustment instrument should have high priority in future research efforts.

Addendum

Individuals who responded to the open-ended questions have provided some direction for further research and inquiry. Respondents corroborated the literature, consistently referring to the stigma that surrounds those who suffer from a mental disorder. What they want is some empathy and understanding of what they are undergoing. The vast majority felt that an increase in education and public awareness of their plight would go a long way to help them cope with their affliction.

To help them cope with periodic and prolonged unemployment, many would like to see an increase in funding for job retraining and counselling for self esteem to help them face the task of reentering the working world. Another option envisioned was short term disability plans for those who are required to take time off from work. This would benefit both the employer and the employee. The employer regains an employee who is already well acquainted with the working environment. The employee can continue to earn a reasonable wage and does not need to undergo the trials and trauma of job re-entry. Employers however, need to be convinced of the potential benefits for all concerned before any movement in policies could be expected.

Employment geared to meet the needs of the chronically mentally ill is minimal, demeaning or nonexistent. Employment sympathetic to periodic disruptions, disability pensions and other safety nets sensitive to the issues of mental disorders need to be created. Policy makers need to be aware of these issues so that

adequate services can be put in place to provide for the long term care of the chronically mentally ill attempting to live in the community.

This study indicated that families identified the need for respite beds and after-hour crisis services to help them cope with occasional mood swings. Many of the services that individuals have identified as lacking are already present in some form or another in the community. It may well be that present services are not being utilized or are being underutilized by the consumer. The issue thus becomes one of raising awareness of these services and facilitating access to the services.

The outcry in many communities against an influx of former patients has clear implications for service providers. The mental health system should provide trained staff skilled in counselling family and friends, willing to make crisis visits when problems occur and able to consult with a broad range of community agencies. Although these functions are implied in the community mental health concept of consultation and education, the focus of such services relative to the severely disabled has not been clearly defined or fully developed.

While recognizing the need of individuals in the community for assistance from the organized service systems, there is also a need to recognize the capacity of the community to provide its own support to mentally disabled persons. There should be specific attention to encouraging mutual and self-help, maximizing natural support systems and avoiding the tendency to do things for

individuals which they or their families and friends could do on their own.

There is a need to encourage local communities to make effective use of existing facilities and resources such as hospitals, community mental health centres, psychosocial rehabilitation agencies, community residences, public and private service agencies and programs designed for the general public. Gaps in services need to be identified, coordination improved among services and availability of assistance to larger numbers of the target population should be assured. There is a need for interagency and intergovernmental collaboration in provision of services to maintain effectiveness without overlap.

The literature strongly supports a conclusion to avoid almost completely the hospitalization of most nonorganic chronically disabled patients through the use of community treatment programs. What is often overlooked is that these positive results are maintained only as long as the special community treatment program is in effect. Even programs that work with patients over long periods of time in the community do not maintain their effects long after the treatment is stopped. Thus it appears that ongoing rather than time limited programs need to be implemented. Chronic mental illness may be a lifelong disability that requires lifelong supports and ongoing interventions if maintenance of improvement is to occur.

References

American Psychiatric Association (1987). Diagnostic and statistical manual of mental disorders (third edition - revised) Washington, D.C.: American Psychiatric Association

Agresti, A & Agresti B.F. (1979). Statistical methods for the social sciences. San Fransisco: Dellen Publishing

Blum, H.L. (1974). Planning for health. New York: Behavioural Publications

Canadian Pharmaceutical Association (1990). Compendium of pharmaceuticals and specialities 25th ed. Ottawa: Canadian Pharmaceutical Association

Crosby, R.L. (1987). Community care of the chronically mentally ill. Journal of Psychosocial Nursing 25 (1) pp. 33-37

Diamond, R. (1985). Drugs and the quality of life: The patient's point of view. Journal of Clinical Psychiatry 46 (5) pp. 29-35

Dillman, D. (1978). Mail and telephone surveys: The total design method. New York: John Wiley & So

Dupuy, H.J. (1977) The General well-being schedule. In McDowell, I and Newell, C. (ed). (1987) Measuring health: A guide to rating scales and questionnaires. New York: Oxford University Press

Egan, J. (1976). Work: The patient's view. Hospital and Community Psychiatry 27 (2) pp. 102-109

Estroff, S.E. (1981). Making it crazy: An ethnography of psychiatric clients in an American community. Berkely: University of California Press

Finnen, G. (1989). Self-help for serious mood disorder: A Manitoba story. Canada's Mental Health 37 (2) pp. 5-7

Freidman, A.M., Kaplan, H.I. & Sadack, B.J. (1982). Modern synopsis of comprehensive textbook of psychiatry. II Edition Baltimore: Williams & Wilkins

Goldberg, D. (1972). The general health questionnaire. In McDowell, I. and Newell, C. (ed). (1987) Measuring health: A guide to rating scales and questionnaires. New York: Oxford University Press

Gottlieb, B. & Coppard, A. (1987). Using social network therapy to create support systems for the chronically mentally disabled. Canadian Journal of Community Mental Health 6 (2) pp. 117-131

- Graham, C. (1992). Inflation lowest in 3 1/2 years. Winnipeg Free Press January 22, 1992 p. A1
- Grimm, P. (1986). Psychotropic medications: Nursing implications. In Rankin, E.A. (ed). Nursing Clinics of North America 21 (3) pp. 397-411
- Hartmann, P. (1988). Understanding the chronically mentally ill. London: Tavistock Publications
- Hassard, T. (1991). Introduction to Biostatistics. Winnipeg: University of Manitoba Class Notes
- Health and Welfare Canada (1988). Mental health for Canadians: Striking a balance. Ottawa: Supply and Services
- House, J.S. (1987). Measures and concepts of social support. In Cohen, S. & Syme, L. (Eds): Social support and health. New York: Academic Press
- Hutchison, P., Lord, J., Savage, H., & Schmarr, A. (1985). Listening: To people who have directly experienced the mental health system. Toronto: Canadian Mental Health Association
- Hutchison, P., Lord, J., & Osborne, W. (1986). Participating with people who have directly experienced the mental health system. Toronto: Canadian Mental Health Association
- Islam, A. (1991) Personal communication. Chief statistician for Community Mental Health Association - Manitoba Region
- Israel, B. & Rounds, R. (1985). Social networks and social support: Living with chronic disease. Patient Education and Counselling 7 pp. 227-247
- Jahoda, M. (1982). Employment and unemployment: A social-psychological analysis. Cambridge University Press
- Jones, K. (1988). Experience in mental health: Community care and social policy. London: Sage publications
- Kirsh, S. (1983). Unemployment: Its impact on body and soul. Toronto: Community Mental Health Association
- Lamb, H.R. & Goertzch, V. (1981). Discharged mental patients: Are they really in the community. Archives of General Psychiatry 24, pp. 29-34
- Leo, J. (1986). Talk is as good as a pill. Time Magazine, May 26, 1986

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Matson, J.L. & Rusch, F.R. (1986). Quality of life: Does employment make a difference? In F.R. Rusch (ed) Competitive employment issues and strategies. Baltimore: Paul H. Brookes pp.331-337

Mechanic, D. (1980). Mental health and social policy (2nd ed) New Jersey: Prentice Hall

Mechanic, D. (1991). Painful choices: Research and essays on health care. New Brunswick: Transaction Publishers

Medernach, C. (1990). Support for unmet needs (S.U.N.): Network and feasibility study. (unpublished) Winnipeg, Manitoba: Mental Health Division

Mitchell, R. & Trickett, E. (1980). Social networks as mediators of social support. Community Mental Health Journal (16) pp. 27-44

Moos, R.H. (Ed.) (1977). Coping with physical illness. New York: Plenum

Moss, J. (1989). Illness and social interaction. New York: John Wiley

Nachman, D. & Nachman, C. (1987). Research methods in the social sciences (3rd ed). New York: St. Martins Press

National Institute of Mental Health (1985). Mood disorders: Pharmacological prevention of recurrences. American Journal of Psychiatry 142 (4) pp. 469-476

Papolos, D.F. & Papolos, J. (1987). Overcoming depression. Toronto: Harper and Row

Patton, M.Q. (1980). Qualitative evaluation methods. Beverly Hills: Sage Publications

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Rioux, M. H. & Crawford, C. (1990). Poverty and disability: Toward a new framework for community mental health. Canadian Journal of Community Mental Health 9 (2) pp. 97-109

Siemiatycki, J. (1979). A comparison of mail, telephone and home interview strategies for household surveys. American Journal of Public Health, 69, pp. 238-244

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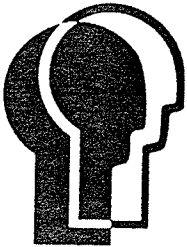
Tolsdorf, C. (1976). Social networks, support and coping: An exploratory study. Family Process (15) pp. 407-427

Weber, T. (1992). Community-based delivery planned. In Winnipeg Free Press, January 22, 1992 pp. B16

Weissman, M. (1971). The social adjustment scale. In (ed) McDowell, I. and Newell, C (1987). Measuring health: A guide to rating scales and questionnaires. New York: Oxford University Press

White, N.F. (1981). The health conundrum. Toronto: T.V. Ontario

World Health Organization Report (1990). Psychological Rehabilitation Journal 14 (1) July pp. 13-21



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Dear member of the Society:

I am writing to ask you for a very important favour. I need about 10 minutes of your time to fill out and return the attached confidential questionnaire.

One of the biggest problems that we as patients have is to gain and keep meaningful employment, allowing us to earn a living and be independent. We know that not having employment leads to increased rehospitalization. If ways could be found to break that cycle, the health care system would benefit greatly.

That is why this questionnaire is so important!

It will identify a patient's present functional levels and answer questions about self-esteem, employment, implications and effects of medications and impact of stigma on patients. It will identify your real needs and concerns - and how it is to live in the community with chronic or recurring depression and manic-depression.

The bottom line is very simple. This survey will help us as patients to receive better services.

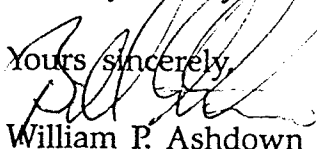
It is vitally important that we receive as many responses as possible. Participation is **voluntary** but the more responses that we have, the more your voice will be heard, and services to you will be improved. Please answer every question.

Let us reassure you that all results are completely confidential. The questionnaire has an identification number for mailing purposes only. This is so we may check your name off the mailing list, when your questionnaire is returned. Your name will never be placed on the questionnaire and no one's name will be released. Survey results will be available later in the Fall, and a summary of the results will be published in an upcoming newsletter.

This survey and the subsequent analysis is being coordinated by a Graduate student, and is to be used as part of a Master's Thesis in Health Education.

If you have any questions, please write or call. Our telephone number is (204)-786-0987. Thank you for your time and assistance.

Yours sincerely,


William P. Ashdown
Executive Director

Roger Macdonald
Graduate Student

If you are not the patient in your family, I would appreciate it if you pass this onto that person so that he or she could fill it out.

Please check the situation that best describes you and/or fill in any blank spaces. All responses are strictly confidential. Thank you for your time.

eg. Male

Marital Status: Divorced

Sex:

Male

Female

Year of Birth: _____

Marital Status: _____

Number of Children/Dependents: _____

Residence:

Winnipeg : _____

Outside Winnipeg: _____

SECTION I - MOOD

1. In the past two weeks, how would you best describe you mood in general:

manic

somewhat manic

neither manic or depressed

somewhat depressed

very depressed

2. In the past two weeks, have you been able to take pleasure or interest in most of your daily activities:

all of the time

most of the time

some of the time

a little of the time

none of the time

3. In the past two weeks, have you been able to sleep well and wake-up feeling rested:

all of the time

most of the time

some of the time

a little of the time

none of the time

4. On average, in the past two weeks, how many hours of sleep per night have you been getting?

greater than 8 hours

6 - 8 hours

4 - 6 hours

2 - 4 hours

1 - 2 hours

5. In the past two weeks, have you felt tired, worn out or exhausted:

all of the time

most of the time

some of the time

a little of the time

none of the time

6. In the past two weeks, how many times has someone told you they were concerned about your behavior?

at least four to five times

at least three times

at least twice

at least once

none of the time

7. How encouraged are you about the long term future?

- I feel very good about my future
- I feel good about my future
- I feel neither good nor bad about the future
- I don't feel good about my future
- the future holds nothing for me

8. In the past two weeks, have you found that your thoughts are going over and over about the same thing?

- all of the time
- most of the time
- some of the time
- a little of the time
- none of the time

9. Do you have others in your extended family who suffer from a mood disorder?

- yes (if yes, how many?) _____
- no

SECTION 2 - INCOME

10. Are you presently receiving Social Assistance, Welfare or Long Term Disability?
If yes, please indicate which one.

- yes
- no

11. Are you:

- employed (paid job)
- a student
- retired
- unemployed
- volunteer (unpaid job)

12. If employed, what is your present job? Please write your occupation in the space below.

13. If employed, how many hours have you worked in the last two weeks?

- 61 - 80 hours
- 41 - 60 hours
- 21 - 40 hours
- 11 - 20 hours
- 0 - 10 hours

14. In the past two weeks, have you been able to work as often as you would have liked?

- yes
- no

15. If no, what stopped you from working as often as you would have liked?

6. Has your illness had a direct influence on your finding and keeping a job?

- yes
- no

17. If yes, in what way?

18. What would help you the most in finding and keeping a job?

19. Have you had enough money to take care of your own and your family's financial needs during the past two weeks?

- I had enough money for my needs
- I usually had enough money with only minor problems
- about half the time I did not have enough money but did not have to borrow money
- I usually did not have enough money and had to borrow from others
- I had great financial difficulty

20. Does your job provide enough income for you to participate in leisure activities?

- yes, I have more than adequate money to participate in leisure activities
- no, I do not have extra money to participate in leisure activities

21. In the past two weeks, have you found your work interesting?

- my work is almost always interesting
- once or twice my work was not interesting
- half the time my work was not interesting
- most of the time my work was not interesting
- my work was always uninteresting

22. What type of living accommodation are you presently in?

- own home
- living with family
- rental property (apartment)
- independent group home
- other _____

SECTION 3 - SOCIAL SUPPORT

23. In the past two weeks, have you had contact with your relatives or extended family?

- I have contacted my relatives regularly
- I have contacted relatives at least once
- I have waited for my relatives to contact me
- I would like to contact them but doubt they would like to contact me
- I avoided my relatives but they contacted me
- I have no contact with my relatives

24. During the past two weeks, have you been able to talk about your feelings and problems with at least one friend or relative:

- I can always talk about my innermost feelings
- I can usually talk about my feelings
- about half the time I felt able to talk about my feelings
- I usually was not able to talk about my feelings
- I was never able to talk about my feelings
- not applicable, I have no friends

25. How many times in the past two weeks have you gone out socially with other people? For example, visited friends, gone to movies, bowling, restaurants, invited friends to your home?

- more than three times
- three times
- twice
- once
- none

26. During the past two weeks how much time have you spent on hobbies or spare-time interests? For example, bowling, sewing, gardening, sport, reading, etc.?

- I spent most of my spare time on hobbies almost every day
- I spent some spare time on hobbies some of the days
- I spent a little spare time on hobbies
- I usually did not spend any time on hobbies but did watch TV
- I did not spend any spare time on hobbies or watching TV

27. Did you depend on your relatives for help, advice, money or friendship during the past two weeks?

- I never need to depend on them
- I usually did not need to depend on them
- about half the time I needed to depend on them
- most of the time I depend on them
- I depend on them

SECTION 4 - MEDICATIONS

28. What medications will you take today? Please list them below along with the amount. (e.g. Lithium 300 mg twice a day).

29. Ignoring any side effects, how helpful are these medications?

- very helpful
- somewhat helpful
- half the time helpful and half the time not helpful
- not helpful

30. Do your medications cause you side effects that interfere with your daily activities?

- not at all
- no more than usual
- rather more than usual
- much more than usual

31. Have you stopped taking medications in the past two weeks because of side effects?

- yes
- no, but I have thought of stopping
- not at all

32. Do you feel that medications run or control your life?

- not at all
- somewhat
- a fair bit of the time
- all of the time

33. If yes, in what way?

34. Has your doctor ever discussed alternatives to your medication and/or discussed alternative therapies (e.g. psychotherapy, behavior therapy)?

- yes, I am currently involved in some form of alternative therapy
- has discussed it and am waiting to enroll in therapy
- has discussed it but I am not interested
- has never discussed alternative therapies with me

SECTION 5 - HEALTH CARE

35. How satisfied are you with the present level of medical care that you are receiving?

- extremely satisfied
- somewhat satisfied
- half the time I am satisfied and half the time I am dissatisfied
- usually dissatisfied
- I have never been satisfied

36. How often are you in contact with a Health professional regarding your illness?

- once a year
- once every 4 - 6 months
- once every 2 - 4 months
- once every month
- once or twice a month

SECTION 6 - COMMUNITY SUPPORT

37. What community programs do you find helpful and relevant to help you cope with your illness? Please list them below.

38. Do you feel that the government/Dept. of Health is doing what it could for those who suffer from mental illness? What changes would you like to see?

39. Any comments on how you feel the Society for Depression and Manic-Depression is helping or benefiting its members? Any comments, criticisms, or suggestions would be welcome.

References

- American Psychiatric Association (1987). Diagnostic and statistical manual of mental disorders (third edition - revised) Washington, D.C.: American Psychiatric Association
- Agresti, A & Agresti B.F. (1979). Statistical methods for the social sciences. San Fransisco: Dellen Publishing
- Blum, H.L. (1974). Planning for health. New York: Behavioural Publications
- Canadian Pharmaceutical Association (1990). Compendium of pharmaceuticals and specialities 25th ed. Ottawa: Canadian Pharmaceutical Association
- Crosby, R.L. (1987). Community care of the chronically mentally ill. Journal of Psychosocial Nursing 25 (1) pp. 33-37
- Diamond, R. (1985). Drugs and the quality of life: The patient's point of view. Journal of Clinical Psychiatry 46 (5) pp. 29-35
- Dillman, D. (1978). Mail and telephone surveys: The total design method. New York: John Wiley & So
- Dupuy, H.J. (1977) The General well-being schedule. In McDowell, I and Newell, C. (ed).(1987) Measuring health: A guide to rating scales and questionnaires. New York: Oxford University Press
- Egan, J. (1976). Work: The patient's view. Hospital and Community Psychiatry 27 (2) pp. 102-109
- Estroff, S.E. (1981). Making it crazy: An ethnography of psychiatric clients in an American community. Berkely: University of California Press
- Finnen, G. (1989). Self-help for serious mood disorder: A Manitoba story. Canada's Mental Health 37 (2) pp. 5-7
- Freidman, A.M., Kaplan, H.I. & Sadack, B.J. (1982). Modern synopsis of comprehensive textbook of psychiatry. II Edition Baltimore: Williams & Wilkins
- Goldberg, D. (1972). The general health questionnaire. In McDowell, I. and Newell, C. (ed). (1987) Measuring health: A guide to rating scales and questionnaires. New York: Oxford University Press
- Gottlieb, B. & Coppard, A. (1987). Using social network therapy to create support systems for the chronically mentally disabled. Canadian Journal of Community Mental Health 6 (2) pp. 117-131

Graham, C. (1992). Inflation lowest in 3 1/2 years. Winnipeg Free Press January 22, 1992 p. A1

Grimm, P. (1986). Psychotropic medications: Nursing implications. In Rankin, E.A. (ed). Nursing Clinics of North America 21 (3) pp. 397-411

Hartmann, P. (1988). Understanding the chronically mentally ill. London: Tavistock Publications

Hassard, T. (1991). Introduction to Biostatistics. Winnipeg: University of Manitoba Class Notes

Health and Welfare Canada (1988). Mental health for Canadians: Striking a balance. Ottawa: Supply and Services

House, J.S. (1987). Measures and concepts of social support. In Cohen, S. & Syme, L. (Eds): Social support and health. New York: Academic Press

Hutchison, P., Lord, J., Savage, H., & Schmarr, A. (1985). Listening: To people who have directly experienced the mental health system. Toronto: Canadian Mental Health Association

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Islam, A. (1991) Personal communication. Chief statistician for Community Mental Health Association - Manitoba Region

Israel, B. & Rounds, R. (1985). Social networks and social support: Living with chronic disease. Patient Education and Counselling 7 pp. 227-247

Jahoda, M. (1982). Employment and unemployment: A social-psychological analysis. Cambridge University Press

Jones, K. (1988). Experience in mental health: Community care and social policy. London: Sage publications

Kirsh, S. (1983). Unemployment: Its impact on body and soul. Toronto: Community Mental Health Association

Lamb, H.R. & Goertzch, V. (1981). Discharged mental patients: Are they really in the community. Archives of General Psychiatry 24, pp. 29-34

Leo, J. (1986). Talk is as good as a pill. Time Magazine, May 26, 1986

- Lord, J., Schnair, A. & Hutchison, P. (1987). The voice of the people: Qualitative research and the needs of the consumer. Canadian Journal of Community Mental Health 6 (2) pp. 25-36
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- Mechanic, D. (1980). Mental health and social policy (2nd ed) New Jersey: Prentice Hall
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- Papolos, D.F. & Papolos, J. (1987). Overcoming depression. Toronto: Harper and Row
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- Pyke, J., Samuelson, G, Shepherd, M & Brown, N (1991). Shaping mental health services. Canadian Nurse 87 (5) 17-19
- Rioux, M. H. & Crawford, C. (1990). Poverty and disability: Toward a new framework for community mental health. Canadian Journal of Community Mental Health 9 (2) pp. 97-109
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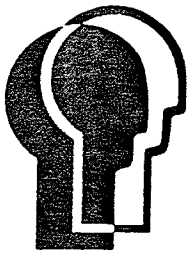
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Weber, T. (1992). Community-based delivery planned. In Winnipeg Free Press, January 22, 1992 pp. B16

Weissman, M. (1971). The social adjustment scale. In (ed) McDowell, I. and Newell, C (1987). Measuring health: A guide to rating scales and questionnaires. New York: Oxford University Press

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The bottom line is very simple. This survey will help us as patients to receive better services.

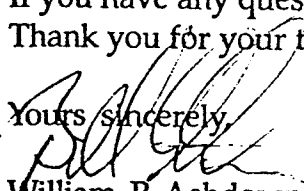
It is vitally important that we receive as many responses as possible. Participation is voluntary but the more responses that we have, the more your voice will be heard, and services to you will be improved. Please answer every question.

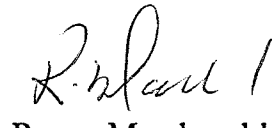
Let us reassure you that all results are completely confidential. The questionnaire has an identification number for mailing purposes only. This is so we may check your name off the mailing list, when your questionnaire is returned. Your name will never be placed on the questionnaire and no one's name will be released. Survey results will be available later in the Fall, and a summary of the results will be published in an upcoming newsletter.

This survey and the subsequent analysis is being coordinated by a Graduate student, and is to be used as part of a Master's Thesis in Health Education.

If you have any questions, please write or call. Our telephone number is (204)-786-0987. Thank you for your time and assistance.

Yours sincerely,


William P. Ashdown
Executive Director


Roger Macdonald
Graduate Student

If you are not the patient in your family, I would appreciate it if you pass this onto that person so that he or she could fill it out.

Please check the situation that best describes you and/or fill in any blank spaces. All responses are strictly confidential. Thank you for your time.

eg. Male

Marital Status: Divorced

Sex:

Male

Female

Year of Birth: _____

Marital Status: _____

Number of Children/Dependents: _____

Residence:

Winnipeg: _____

Outside Winnipeg: _____

SECTION I - MOOD

1. In the past two weeks, how would you best describe your mood in general:

manic

somewhat manic

neither manic or depressed

somewhat depressed

very depressed

2. In the past two weeks, have you been able to take pleasure or interest in most of your daily activities:

all of the time

most of the time

some of the time

a little of the time

none of the time

3. In the past two weeks, have you been able to sleep well and wake-up feeling rested:

all of the time

most of the time

some of the time

a little of the time

none of the time

4. On average, in the past two weeks, how many hours of sleep per night have you been getting?

greater than 8 hours

6 - 8 hours

4 - 6 hours

2 - 4 hours

1 - 2 hours

5. In the past two weeks, have you felt tired, worn out or exhausted:

all of the time

most of the time

some of the time

a little of the time

none of the time

6. In the past two weeks, how many times has someone told you they were concerned about your behavior?

at least four to five times

at least three times

at least twice

at least once

none of the time

7. How encouraged are you about the long term future?

- I feel very good about my future
- I feel good about my future
- I feel neither good nor bad about the future
- I don't feel good about my future
- the future holds nothing for me

8. In the past two weeks, have you found that your thoughts are going over and over about the same thing?

- all of the time
- most of the time
- some of the time
- a little of the time
- none of the time

9. Do you have others in your extended family who suffer from a mood disorder?

- yes (if yes, how many?) _____
- no

SECTION 2 - INCOME

10. Are you presently receiving Social Assistance, Welfare or Long Term Disability?
If yes, please indicate which one.

- yes
- no

11. Are you:

- employed (paid job)
- a student
- retired
- unemployed
- volunteer (unpaid job)

12. If employed, what is your present job? Please write your occupation in the space below.

13. If employed, how many hours have you worked in the last two weeks?

- 61 - 80 hours
- 41 - 60 hours
- 21 - 40 hours
- 11 - 20 hours
- 0 - 10 hours

14. In the past two weeks, have you been able to work as often as you would have liked?

- yes
- no

15. If no, what stopped you from working as often as you would have liked?

16. Has your illness had a direct influence on your finding and keeping a job?

- yes
- no

17. If yes, in what way?

18. What would help you the most in finding and keeping a job?

19. Have you had enough money to take care of your own and your family's financial needs during the past two weeks?

- I had enough money for my needs
- I usually had enough money with only minor problems
- about half the time I did not have enough money but did not have to borrow money
- I usually did not have enough money and had to borrow from others
- I had great financial difficulty

20. Does your job provide enough income for you to participate in leisure activities?

- yes, I have more than adequate money to participate in leisure activities
- no, I do not have extra money to participate in leisure activities

21. In the past two weeks, have you found your work interesting?

- my work is almost always interesting
- once or twice my work was not interesting
- half the time my work was not interesting
- most of the time my work was not interesting
- my work was always uninteresting

22. What type of living accomodation are you presently in?

- own home
- living with family
- rental property (apartment)
- independent group home
- other _____

SECTION 3 - SOCIAL SUPPORT

23. In the past two weeks, have you had contact with your relatives or extended family?

- I have contacted my relatives regularly
- I have contacted relatives at least once
- I have waited for my relatives to contact me
- I would like to contact them but doubt they would like to contact me
- I avoided my relatives but they contacted me
- I have no contact with my relatives

24. During the past two weeks, have you been able to talk about your feelings and problems with at least one friend or relative:

- I can always talk about my innermost feelings
- I can usually talk about my feelings
- about half the time I felt able to talk about my feelings
- I usually was not able to talk about my feelings
- I was never able to talk about my feelings
- not applicable, I have no friends

25. How many times in the past two weeks have you gone out socially with other people? For example, visited friends, gone to movies, bowling, restaurants, invited friends to your home?

- more than three times
- three times
- twice
- once
- none

26. During the past two weeks how much time have you spent on hobbies or spare-time interests? For example, bowling, sewing, gardening, sport, reading, etc.?

- I spent most of my spare time on hobbies almost every day
- I spent some spare time on hobbies some of the days
- I spent a little spare time on hobbies
- I usually did not spend any time on hobbies but did watch TV
- I did not spend any spare time on hobbies or watching TV

27. Did you depend on your relatives for help, advice, money or friendship during the past two weeks?

- I never need to depend on them
- I usually did not need to depend on them
- about half the time I needed to depend on them
- most of the time I depend on them
- I depend on them

SECTION 4 - MEDICATIONS

28. What medications will you take today? Please list them below along with the amount. (e.g. Lithium 300 mg twice a day).

29. Ignoring any side effects, how helpful are these medications?

- very helpful
- somewhat helpful
- half the time helpful and half the time not helpful
- not helpful

30. Do your medications cause you side effects that interfere with your daily activities?

- not at all
- no more than usual
- rather more than usual
- much more than usual

31. Have you stopped taking medications in the past two weeks because of side effects?

- yes
- no, but I have thought of stopping
- not at all

32. Do you feel that medications run or control your life?

- not at all
- somewhat
- a fair bit of the time
- all of the time

33. If yes, in what way?

34. Has your doctor ever discussed alternatives to your medication and/or discussed alternative therapies (e.g. psychotherapy, behavior therapy)?

- yes, I am currently involved in some form of alternative therapy
- has discussed it and am waiting to enroll in therapy
- has discussed it but I am not interested
- has never discussed alternative therapies with me

SECTION 5 - HEALTH CARE

35. How satisfied are you with the present level of medical care that you are receiving?

- extremely satisfied
- somewhat satisfied
- half the time I am satisfied and half the time I am dissatisfied
- usually dissatisfied
- I have never been satisfied

36. How often are you in contact with a Health professional regarding your illness?

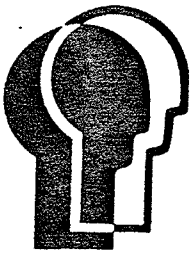
- once a year
- once every 4 - 6 months
- once every 2 - 4 months
- once every month
- once or twice a month

SECTION 6 - COMMUNITY SUPPORT

37. What community programs do you find helpful and relevant to help you cope with your illness? Please list them below.

38. Do you feel that the government/Dept. of Health is doing what it could for those who suffer from mental illness? What changes would you like to see?

39. Any comments on how you feel the Society for Depression and Manic-Depression is helping or benefiting its members? Any comments, criticisms, or suggestions would be welcome.



THE SOCIETY FOR DEPRESSION AND MANIC-DEPRESSION OF MANITOBA INC.

PROVINCIAL OFFICE: 4-1000 NOTRE DAME AVENUE, WINNIPEG, MANITOBA R3E 0N3 - (204) 786-0987

Dear Society Member,

About two weeks ago we sent you a questionnaire seeking your opinions about what it is like to live in the community with chronic or recurring depression or manic depression. Your name was selected from the mailing list of the Society for Depression and Manic Depression.

If you have already completed and returned the questionnaire to us, please accept our sincere thanks. If not, we ask you to do so today. Because we need to hear from all of our members it is most important that your opinions et cetera be included in this study if the results are to be an accurate representation of the opinions of the Society's membership.

If by some chance you did not receive the questionnaire, or it was misplaced, please call us right now at 786-0987 (collect) and we will get one in the mail to you today.

Sincerely,

William Ashdown
Executive Director

Roger Macdonald
Graduate Student