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Needs, supports, burden, and affect the experiences of family members of individuals with mental illness

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Needs, Supports, Burden, and Affect:
The Experiences of Family Members of Individuals with Mental Illness

by

Lysanne Chénier

Honours Bachelor of Arts, Laurentian University, 1988

THESIS

Submitted to the Department of Psychology
in partial fulfilment of the requirements
for the Master of Arts degree
Wilfrid Laurier University
1990

For my Mother and Father

Abstract

The purpose of this research project was to examine the needs and supports of family members of people with schizophrenia and to determine the relationship between needs, supports, objective burden, negative affect, and positive affect. The participants were 32 family members of a self-help and support group catering to the families of people with schizophrenia. Three categories of needs and supports were examined. These three categories included: problem-solving, financial and tangible assistance, and social-emotional needs and supports. Family members discussed: the degree of need and support, who currently meets the need, issues and concerns, and suggestions about who might best meet the needs and how. Family members experienced greater need than support across all three categories. Family members themselves and the community self-help and support group were key resources. Issues and concerns focused on the aspects of need that must be addressed in order for programs and policies to be successful. Suggestions about who might best meet the need and how revealed that family members have a clear understanding of existing problems and have clear solutions about how to address their needs. Another aspect of the action-oriented strategies of this study was a discussion of other themes. These themes were not directly related to specific needs but to groups of needs. Again, clear and practical suggestions were made about how to address these issues at a community level.

Theoretical questions examined the relationship between needs and supports, on the one hand, and affect and stress on the other hand. Positive and negative affect were independent of each other. Negative affect was directly related to the level of financial and tangible assistance needs. Social-emotional support was directly related to positive affect and inversely related to negative affect. There was no evidence that needs and supports interacted to predict objective burden, positive affect, or negative affect consistent with the stress-buffering hypothesis. The implications for future research center on attempting to provide an optimal "fit" between need and support in community-based agencies. Existing programs should be evaluated to determine if programs meet the needs of those who make use of the programs. If supports are in place, stress can be reduced. Programs should provide support as a part of service delivery. Researchers should focus on making use of mental health users and family members to elicit their ideas about program design, implementation and methods for providing support.

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Table of Contents

List of Tables

Needs, Supports, Burden, and Affect: The Experiences of Family Members of Individuals with Mental Illness

Introduction

The deinstitutionalization of psychiatric patients has vastly increased the responsibility of the family of the mentally ill individual (Grad & Sainsbury, 1968; Smith, 1969; Robbins & Robbins, 1974; Hatfield, 1978; Pai & Kapur, 1982; Thompson & Doll, 1982; Montgomery, Gonyea & Hooyman, 1985; Platt, 1985; St. Onge & Lavoie, 1987). This is because ex-patients need their family's help when they return to the community (Appleton, 1974). Many ex-patients return to their family's home upon discharge. Some researchers have reported that two-thirds of the patients in their studies returned to the homes of their families following an inpatient episode (Michaux, Krutz, Kurland & Gansereit, 1969; Reich & Seigel, 1973; Davis, Dinitz & Pasamanick, 1974). These families are then pulled into critical caregiving roles (Kreissman & Joy, 1974; Doll, 1976; Hatfield, 1978; Test & Stein, 1980; Thompson & Doll, 1982). This occurs because the family is often the only social network for the patient (Cohen & Sokolovsky, 1978; Fisher & Tessler, 1986). Some researchers have reported that this creates considerable stress for these families (Appleton, 1974; Robbins & Robbins, 1974; Doll, 1976; Anderson, 1977; Marcus, 1977; Robinson & Thurmher, 1979; McCubbin, Joy, Cauble, Comeau, Patterson & Needle, 1980; Leavy, 1983; Horowitz & Dobrof, 1982).

Community psychologists are concerned with this social problem (Heller, Price Reinharz, Riger & Wandersman, 1984). Community psychologists focus on an ecological perspective "which emphasizes the relationship between people and their environments rather than examining the characteristics of either in isolation" (Heller et al., 1984, p. 118). The problems experienced by families of people with schizophrenia may be examined from this perspective.

The Ecological Approach to Community Psychology

The ecological perspective applied to the needs of family members of the mentally ill. The ecological framework of the effects of deinstitutionalization on family members can be described in terms of four principles that Mills and Kelly (1972) proposed as a guide to the planning of community interventions. These four principles are: interdependence, the cycling of resources, adaptation, and succession (Kelly, 1966; Mills & Kelly, 1972). The principle of interdependence can be described in terms of community intervention and its effects. "Intervention in one community problem, or with one community agency, invariably will have an effect on other community problems or agencies" (Heller et al., 1984, p. 121). This principle can be applied to the social problems arising from deinstitutionalization. As has been noted, deinstitutionalization resulted in an increase in family responsibility and stress. Thus, changes in the policy created unintended side-effects for families. The second principle, the cycling of resources is concerned with the definition and distribution of resources. The families of people with schizophrenia are often the major resource to the family member with a mental illness, and they would benefit from an increase in resources which respond to their needs. For instance, psychoeducational programs have been found to reduce family stress, which may in turn benefit the family member with a mental illness

(Falloon, Boyd, & McGill, 1984; Leff, Kuipers, Berkowitz, Eberlein-Vries & Sturgeon, 1982; Seeman, 1988). The principle of adaptation from the ecological perspective refers to the strengthening of community resources "so that those people in transition--those in the process of adapting to new roles and new environments--will find the necessary supports" (Kelly, 1966, in Heller et al., 1984, p. 122). When this principle is applied to the problems of families of people with schizophrenia, it is obvious that community resources which would educate families at the onset of the illness, providing crisis services and support during hospitalization may help families deal with the illness. These resources should help families adapt to the role they often assume as caregivers for an adult with schizophrenia. The last principle, succession, was described as: "(1) the orderly process of community changes; these are directional, and therefore predictable; (2) it results from the modification of the physical environment by the community; (3) it culminates in the establishment of as stable an ecosystem as is possible on the site in question" (Heller et al., 1984, p. 122). This principle is also applicable to the problems that families of ex-patients experience. "Deinstitutionalization" was not an "orderly" change. Unfortunately, many of the programs and services were not available to meet the needs of ex-patients and their families. This has created problems for families and has resulted in a need for a new approach. The new approach adopted by community psychologists is based on the ecological perspective. According to this new approach, the needs of ex-patients and family members should be considered when attempts are made to direct community resources to address the problems.

The ecological perspective applied to action research aimed at meeting the needs of families of the mentally ill. Trickett (1984) proposed an "ecological metaphor" which served as a heuristic for how to take the environment into account when designing community based research (Trickett, 1984, p. 267). Thus, the structure of research relationships should reflect the paradigm premises of the ecological perspective in research. Trickett (1984) outlined three possible ways that this might be accomplished. First, "the creation of a local citizen group to aid in the design of the research, provide feedback on unanticipated side effects, interpret data by providing comments about what, in that particular culture, the data might mean and decide how the data might be most useful to members of the setting," (Trickett, 1984, p. 274). The formation of an advisory committee comprised of individuals with schizophrenia, family members and health care professionals from agencies in the community could perform these tasks and fulfill the roles outlined by Trickett (1984). Also, my role as the researcher should be to help the advisory committee to outline the mandate of this committee and provide guidance when it is needed. Second, "allowing the time and affirming the value of having the research team act as a resource conduit between the community setting and the university" (Trickett, 1984, p. 274). In this study, it was important that the time be taken for the advisory committee to have input on the design of the study, of the measurement tools, and on the procedure for feedback. This served two functions. First, the members of the advisory committee would recognize that their input is crucial to the research. Second, the gap between the university as an "institution" and the community setting would be decreased as both were be engaged in a cooperative endeavour in which the input from both settings would be recognized as legitimate. The third possible way that research relationships should reflect paradigm premises is by "instituting regularized process meetings with key citizens to assess how the community setting is experiencing the work and how the research team is perceiving the community setting" (Trickett, 1984, p. 274). In order to do this, I made use of key informants in the community. In this study, three groups of key informants were used. The first group included health care professionals so that the impact of the research on family members and on ex-patients could be observed and noted. The second group included representatives of self-help and support groups for family members. The third group included supervisors in the university setting so that I had an opportunity to provide reports on the meetings and then have a forum where I could receive some feedback on how to address these impacts. Meetings with key informants from each group took place before the study was designed, during the design and procedure, when feedback was provided and when the study was completed.

Community psychologists often choose action-oriented strategies for community research (Heller et al., 1984). Lewin (1951) was one of the first to promote the action research tradition via "a cyclical process of fact-finding, action, and evaluation" (Heller et al., 1984, p. 91). O'Neill and Trickett (1982) proposed that when research was oriented to action, it was aimed at changing some characteristic of an individual, group, or community. The use of action-oriented strategies in this study was the basic premise for promoting change in order to better meet the needs of families of people with schizophrenia. First, the "fact-finding" described by Lewin (1951) involved the identification of needs and the degree of these needs. The "action" described by Lewin (1951) was the measure of need and the collection of suggestions made by family members about how these needs might best be met. There were other aspects of "action" in this study. First, the formation of an advisory committee and the action taken by these members was a form of "action." Another form of "action" was making use of a workshop to report the findings of the study to those responsible for service delivery and to bring together health care providers, family members and mental health users so that they may work together to foster change. A third form of "action" was the formation of a coalition which would devote itself to meeting needs of family members. The "evaluation" described by Lewin (1951) is the evaluation of the results of action strategies or programs. This evaluation begins the cycle again as the first step to evaluation is "fact finding" (Heller et al., 1984). The premise of action-oriented research in this study fostered "evaluation" once the "action" strategies have been implemented.

Summary. Community psychologists are concerned about the experience of the families of people with schizophrenia. The emphasis is on matching needs with resources to provide an optimal "fit" between the person and the environment. The purpose of this thesis was: (1) to determine the needs of families of ex-patients, (2) to ascertain whether or not these needs are being met, (3) to discover family issues and concerns about their needs, and (4) to collect information about how policies and programs should be changed in order to match family needs and community resources. The following literature was reviewed: the impact of the ex-psychiatric patient on the family, the needs of the families of ex-psychiatric patients, and resources and support for families of ex-psychiatric patients. The literature reflected a need for an ecological approach with action-oriented strategies in the study of family needs and for family support by emphasizing the need for a match between their needs and available resources.

Families of the Mentally Ill

Impact of the ex-patient on the family. In order to assess the experiences of families of people with schizophrenia, researchers have devised scales to measure the degree of burden that families experience. Pai and Kapur (1982) described burden as "social disturbance, family distress and number of reported problems." Smith (1969) defined burden as "a determinant of the effect of having the patient at home as perceived by the person most closely associated with him," while Thompson and Doll (1982) described burden as "the social and emotional costs of those families charged with caring for their mentally ill kin."

Platt and Hirsch (1981) recognized "the importance of separating events, happenings, and activities from feelings, attitudes, and emotions." These two areas were described as objective versus subjective burden, respectively. Platt (1985) described these two dimensions of burden. Objective burden involved "any disruption to family/household life which is potentially verifiable and observable," while subjective burden included "personal feelings of carrying a burden, being distressed, unhappy, upset, etc." (Platt, 1985). Objective and subjective burden are considered to be two different measures of the construct of burden. Potasznik and Nelson (1984) found that family members' scores on the subjective and objective burden measures were significantly correlated (r=.71).

The items which measure objective and subjective burden are distinctly different. Items which measure objective burden examine such issues as the frequency of loss of work due to the ex-patient, missing school due to the ex-patient, the interruption of social and leisure activities, the disruption of household or domestic routines and difficulties with neighbors due to the ex-patient (Test & Stein, 1980). Items which measure subjective burden examine the frequency of emotions about the ex-patient. Some of these emotions include: worry, feeling unable to cope, depression, anger, worried about the care of the ex-patient in the future, the stress and strain due to the ex-patient (Test & Stein, 1980).

The items on the subjective burden scale focus on negative emotions toward the ex-patient. The absence of negative emotions or affect does not ensure positive emotions. Researchers have found that positive and negative affect are two independent dimensions (Bradburn & Caplovitz, 1965; Bradburn, 1969; Diener & Emmons, 1985; Watson, Clark & Tellegen, 1988). A measure of subjective experience should include both positive and negative emotions. Watson, Clark and Tellegen (1988) developed and validated the PANAS scale which measures the frequency of positive emotions such as interest, excitement, strength, enthusiasm, pride, alertness, inspiration, determination, attentiveness and activity, and the frequency of negative emotions such as distress, upset, guilt, being scared, hostility, irritability, shame, nervousness, jitteriness, and fear experienced. In this study, we decided to use the PANAS scale for both theoretical and ethical reasons. In terms of theory, we thought that family members would experience both positive and negative feelings with respect to their family member with a mental illness, and that these two dimensions might be independent of one another. In terms of ethics, we thought that asking questions only about negative feelings might lead to a preoccupation with their negative experiences and a tendency to stereotype the ex-patient as a "burden."

Thompson and Doll (1982) reviewed literature which supported the family experience of objective burden. In Thompson and Doll's (1982) study, 20 to 50 percent of the families of people with schizophrenia experienced objective burden as a result of caring for the ex-patient. This burden included neglecting responsibility to other family members, financial burden, disruption of social life, interference with everyday routines, and problems with relationships with neighbors. In their sample, 73 percent of the participants who experienced objective burden were adversely burdened; 43 percent were moderately burdened; and 23 percent were severely burdened.

Several studies have examined the correlates of burden experienced by family members of the mentally ill. Noh and Avison (1988) found that burden was related to the relationship to the ex-patient, sociodemographic variables such as low income and unemployment, psychiatric factors such as length of hospital stay and severity of symptoms, family environment factors such as little social support available, and stress. In Potasznik and Nelson's (1984) study, self-help group supportiveness, spouse time spent with patient, psychiatric symptomatology and the ex-patient's place of residence were correlated with burden. Montgomery et al. (1985) found that age and income of caregivers and caregiving tasks that confine the caregiver temporarily or geographically were predictors of the experience of burden. Thus, it has been shown that the experience of burden is correlated with various aspects of the experience of family members of ex-patients. Higher levels of burden were noted in families characterized by low income, unemployment, having little or no social support, and where ex-patients live in the parental home and the caregivers are parents.

Needs of families of ex-psychiatric patients. Recently, mental health professionals have noted the importance of the family's contribution to the care of the ex-patient (Grad & Sainsbury, 1968; Smith, 1969; Coe, Curry & Kessler, 1969; Welldon, 1971; Appleton, 1974; Caplan, 1974; Kreissman & Joy, 1974; Robbins & Robbins, 1974; Doll, 1976; Anderson, 1977; Marcus, 1977; Eaton, 1978; Hatfield, 1979; Pai & Kapur, 1980; Test & Stein, 1980; Potasznik & Nelson, 1984; Fisher & Tessler, 1986; Schultz, House & Andrews, 1986; St. Onge & Lavoie, 1987). This has been a welcome change, because in the past families were often blamed for the disease and few attempts were made to deal with their needs and anxieties (Appleton, 1974; Kreissman & Joy, 1974; Maxman, Tucker & Lebow, 1974; Anderson, 1977; Hatfield, 1978; Geist, 1985; Schultz et al., 1986). Studies in psychiatric aftercare are now beginning to focus on various issues and problems that families encounter as a result of caring for the person with schizophrenia (Freeman & Simmons, 1963; Hoenig & Hamilton, 1969; Doll, 1975; Marcus, 1977; McCubbin et al., 1980; Potasznik & Nelson, 1984; Montgomery et al., 1985; Platt, 1985; Biegel & Yamatani, 1986; Drescher, 1986; St. Onge & Lavoie, 1987).

Researchers have begun to realize that the families of people with schizophrenia have special needs (Grad & Sainsbury, 1968; Appleton, 1974; Maxman et al., 1974; Marcus, 1977; McCubbin et al., 1980; St. Onge & Lavoie, 1987). St. Onge and Lavoie (1987) ranked the needs of family members based on the frequency of response of the family members in their study. The following needs were identified and were ranked from the highest level of need to the lowest: employment centres for ex-patients, housing, follow-up by mental health professionals, clear instructions at times of crisis, respite care, more community activities for the ex-patient, education, support from family and friends, individual counselling, family therapy and financial assistance (St. Onge & Lavoie, 1987). These needs arise from the responsibility that families must assume (Smith, 1969; Cohen & Sokolovsky, 1978; McCubbin et al., 1980; Biegel & Yamatani, 1986; Fisher & Tessler, 1986). These responsibilities include providing living accommodations for the ex-patient (Michaux et al., 1969; Reich & Seigel, 1973; Davis et al., 1974; Leaf, 1977; Thompson & Doll, 1982), managing the illness (Hatfield, 1979; St. Onge & Lavoie, 1987), dealing with the ex-patient's crises (Anderson, 1977), trying to motivate the individual (Hatfield, 1978), being primary caregivers (Grad & Sainsbury, 1963), and providing financial support (Potasznik & Nelson, 1984).

Recognition of family needs is crucial to the development of programs and policy (Anderson, 1977; Marcus, 1977; Geist, 1985; St. Onge and Lavoie, 1987). Their experiences also provide insight into the etiology of these needs. Appleton (1974) found that families are upset, in need of support, and should be given help and treated with respect. Robbins and Robbins (1974) discussed the interference with routine family living these families experience, as did Doll (1975) and St. Onge and Lavoie (1987). Marcus (1977) proposed that families need reassurance, recognition, praise and support. Anderson, Hogarty and Reiss (1981) found that families of people with schizophrenia varied in their levels of "expressed emotion," including criticism and over-involvement with the ex-patient. They also found that high levels of "expressed emotion" contributed to recidivism rates in ex-patients (Anderson et al., 1981). Hatfield (1978) recommended providing help for families that was specific to their needs, as did Geist (1985), Biegel and Yamatani (1986), St. Onge and Lavoie (1987), and Marcus (1977).

Some of these specific needs could be met by providing help to families so that they can manage the disorder, and providing them with respite care (Hatfield, 1978), providing support, education, counselling, crisis intervention services for the families, continuity of care for the ex-patient (Geist, 1985) and providing economic assistance to ex-patients and their families (Biegel & Yamatani, 1986). At this time, it is recognized that providing these services would be beneficial to family members as it could reduce the degree of stress and isolation they experience.

Family members of the mentally ill experience a variety of needs. It would be helpful to categorize these needs into three different categories: problem-solving needs, tangible needs, and social-emotional needs (Nelson, 1987). Problem-solving needs could include needs that might be met through the provision of information and guidance about the disorder and its management. Tangible needs could include needs that might be met through the development of services and programs for the ex-patient. Finally, social-emotional needs could include needs that might be met through the provision of social and emotional support from others for the family members.

Problem-solving needs could include all needs related to advice and guidance. Some of these needs include: need for information about the disorder (symptoms, onset, prognosis, etc.), need for information about medications, their effects and side effects, advice on how to deal with the ex-patient when she/he becomes disturbed or symptomatic, advice on what to reasonably expect the ex-patient to be able to do, advice on how to deal with the ex-patient's level of motivation, and information on what services or community resources are available for the ex-patient. In the past, researchers have classified these problem-solving needs as a single need for education. It is clear that within this need for education, many issues involve problem-solving for family members and that they need help with these issues.

Tangible needs are those that can be met through the provision of service for the ex-patient. Some of these needs include the need for supportive employment, housing, educational opportunities, financial assistance, help from outside the family with meals and household chores, help with money management for the ex-patient, and respite care. Each of these needs may be met through funding and/or the creation services for ex-patients.

Social-emotional needs could be met by other individuals such as relatives, friends, para-professionals, professionals, and self-help groups. Some of these needs include the need to have someone to talk with when the family member is frustrated or angry, or feeling guilty or worried, the need to have someone acknowledge and compliment the family member on how helpful she/he has been to the ex-patient, the need for someone to talk with when the family member is worried about the future of the ex-patient, someone to express interest and concern in the well-being of the ex-patient, and someone who allows the family member to confide her/his concerns about the patient. Each of these needs could be met through the provision of social and emotional support.

Dividing family needs into these three categories is useful in two ways. First, the categorization of needs allows researchers to examine groups of needs and how they are related to each other. Second, this categorization allows practitioners to design programs and create policies which may address a group of needs instead of one individual need.

Resources and supports for families of ex-psychiatric patients. Some researchers have examined the methods families use to cope. One emerging trend for coping has been the use of self-help groups (Biegel & Yamatani, 1986; Drescher, 1986; Schultz et al., 1986). Researchers have noted that families of people with schizophrenia have formed mutual self-help groups in order to receive and provide support for each other. These self-help groups may alleviate objective and subjective burden, as they attempt to address the needs of members. Researchers who have studied the activities of self-help groups for families of individuals with schizophrenia have reported that the groups provide education about the disorder, information about methods of coping, methods to help the "patient," and a vehicle for advocacy (Drescher, 1986; Schultz et al., 1986). The groups also help families to manage patient symptomatology and reduce the isolation experienced by family members (Biegel & Yamatani, 1986). One of the most crucial roles of the self-help group is that of acknowledging the needs of family members (Hatfield, 1978, 1979). In this way, the self-help group provides social and emotional support for the family (Hatfield, 1979).

The notion of the need for support for families of people with schizophrenia has been noted by some researchers (Grad & Sainsbury, 1968; Smith, 1969; Hatfield, 1978, 1979; Pai & Kapur, 1982; Thompson & Doll, 1982; Potasznik & Nelson, 1984; Geist, 1985; Biegel & Yamatani, 1986; Drescher, 1986; Schultz et al., 1986; Anderson, 1987; St. Onge & Lavoie, 1987). At this time little research has been done to determine what type of support is needed to decrease objective burden and negative affect and to promote positive affect, and what type of support would in turn respond to the needs of family members. Aside from theories of social and emotional support, little research has been done to describe what types of support could correspond to specific needs of families of people with schizophrenia.

Nelson (1987) reviewed the literature on social support. He developed a description and framework for theories of support. Nelson (1987) described three types of support: problem-solving support, tangible support, and social-emotional support. These types of support correspond to the types of needs outlined earlier.

Social-emotional support was described as two distinct types of "emotionally sustaining" interactions: non-directive support or emotional support and positive social interaction or socializing (Barrera & Ainley, 1983; Nelson, 1987; Vaux, Riedel & Stewart, 1987). Tangible support includes financial or practical help from an agency, service or person. Problem-solving support involves receiving help from an individual to help resolve some problem or dilemna and includes information and guidance.

Social-emotional, tangible, and problem-solving support are especially relevant when researchers consider the needs of families of people with schizophrenia. Social-emotional support may address needs such as stress and isolation, and may result in increased sense of recognition, affiliation and support for family members. Tangible support may address needs for respite care, financial assistance, education, employment, and housing for the ex-patient. Finally, problem-solving support may address needs for information and education for family members, and may help to reduce the difficulties encountered in day-to-day living with the patient.

The categorization of needs of family members is helpful as it is easier to describe the type of support required to meet the need. In this study, the application of a framework to categorize need and support will permit the researcher to design a measure which can measure specific needs and the specific types of support required to meet those needs. Also, when family members' needs are considered in this framework, the experience of burden and emotion can also be addressed.

The use of measures of support as predictors of well-being has been supported by research (Mitchell, Billings & Moos, 1982; Broadhead, Kaplan, James, Wagner, Schoenbach, Grimson, Heyden, Tiblin & Gehlbach, 1983; Leavy, 1983). There are two models of how social support may be related to emotional well-being: the "direct" effect and the "indirect" or interaction effect model. The direct effects model posits that social support will be directly related to well-being. Cohen and Wills (1985) discussed the indirect effects model in which support is related to well-being for individuals under stress because the support acts as a "buffer" or protects people from the influence of stressful events. Both the direct effects model and the "stress buffering" model are applicable in this study. Social-emotional, tangible, and problem-solving support may act as a "buffer" for families of individuals with schizophrenia. If support does act as a buffer, the experience of burden and of negative emotion should be lower for individuals with support and higher for family members with little support. Also, support may be directly related to burden and affect, independent of one's needs or stress levels.

Summary-Action Goals-Questions

Summary. The literature supports the observation that families of people with schizophrenia are experiencing an increased responsibility for caring for mentally ill family members due to deinstitutionalization (Grad & Sainsbury, 1968; Smith, 1969; Robbins & Robbins, 1974; Pai & Kapur, 1982; Thompson & Doll, 1982; Noh & Avison, 1988; Solomon, Beck & Gordon, 1988). As a result, families have special needs (Grad & Sainsbury, 1968; Appleton, 1974; Maxman et al.. 1974; Marcus, 1977; McCubbin et al., 1980; St. Onge & Lavoie, 1987). Mental health professionals have begun to note the contribution of family members and to recognize their needs (Potasznik & Nelson, 1984; Geist, 1985; Drescher, 1986; Schultz et al., 1986; St. Onge & Lavoie, 1987). This interest in the family experience has prompted researchers to examine the levels of burden experienced by family members (Platt & Hirsch, 1981; Potasznik & Nelson, 1984; Platt, 1985). While research has been conducted on family members, little action has been taken by professionals to help them (Hatfield, 1979). Thus families have developed their own coping mechanisms (St. Onge & Lavoie, 1987). One of these mechanisms has been the development and use of mutual self-help groups (Biegel & Yamatani, 1986; Drescher, 1986). These groups have provided families with some of the support they need (Geist, 1985; Biegel & Yamatani, 1986).

Nelson's (1987) framework for categorizing the types of support is a "good fit" for the study of needs of families of people with schizophrenia, as their needs fall into each of the three categories. The present study examined family needs, supports, burden, and affect. The interaction between the actual need, the support received, and the level of objective and subjective emotions experienced by family members were assessed.

Action goals. There were four action goals for the study:

1. To develop a profile of social-emotional, tangible, and problem-solving needs of families.

2. To find out which of these needs are being met and which are not.

3. To generate issues and concerns from the perspective of family members.

4. To generate program and policy suggestions from the perspective of family members.

Research questions. There were three research questions:

1. How are needs for social-emotional, tangible, and problem-solving support related to objective burden, negative affect, and positive affect?

2. How is the receipt of social-emotional, tangible, and/or problem-solving support related to objective burden, negative affect, and positive affect?

3. Do needs and supports interact to predict objective burden, negative affect, and positive affect, in accordance with the stress buffering hypothesis?

Method

Context and Entry

Thunder Bay was selected as an ideal location to conduct this study. I was a native of North Eastern Ontario and planned to return to the north once my education was completed. The North Western part of the province seemed like an ideal location for the study for personal and professional reasons.

The City of Thunder Bay is actually two cities that were amalgamated, Fort William and Port Arthur. With a population exceeding 110,000, it is the cultural and medical center for North Western Ontario. The populace of outlying communities come to Thunder Bay to obtain goods and services that are not available in their smaller communities. One service that is widely used is Lakehead Psychiatric Hospital. It is the only psychiatric facility east of Winnipeg and west of North Bay. Thus, Thunder Bay is seen as the center for services for the mentally ill. It is also the center with the most developed community-based programs for the psychiatrically disabled. Contrary to popular belief, the North West of this province is rich in resources for the psychiatrically disabled. Funding has steadily increased over the years and many community-based programs were developed and implemented.

The Office of the Secretary of State and the Office of Disabled Persons in Thunder Bay expressed an interest in the needs of the psychiatrically disabled in this community. The Director of the Thunder Bay chapter of Ontario Friends of Schizophrenics and the researcher prepared a proposal of the costs of the study and applied for funding from these two agencies. Funding was approved by both agencies. The Office of the Secretary of State contributed approximately $7000.00 for the research and the Office of Disabled Persons contributed approximately $2000.00 for the workshop. I was given an honorarium of $5000.00 to conduct the study and $1000.00 to conduct the workshop.

Initial Contact with Participants

The President of the Thunder Bay chapter of Ontario Friends of Schizophrenics, Bob Schumacher, contacted the members of the self-help and support group by telephone between the months of September, 1988, and December, 1988. The President of this group was a member of the research advisory committee; he was well informed about the nature and purpose of the study; and he was able to describe the study to participants. The President also discussed the process of the study, the funding received, the media campaign, and the goals and objectives of the study with the membership.

Bob Schumacher and his wife, Helen, played a vital role in the research process. They not only recruited participants, but they opened their home and their hearts to me. Many times they took responsibility for transportation for me and/or the participants. They set up a private and informal office in their home where I could work and interview participants. Hot home-cooked meals and many pots of coffee and tea were prepared. Bob and Helen were always available and very supportive of me. Their guidance, friendship, input and energy were key contributing factors to the success of the study and the workshop.

I was introduced to each person before he or she agreed to participate. I gave the participant a written outline of the goals and objectives of the study and the rights of the participants (see Appendix B). The family member and I discussed this information to ensure that the person clearly understood his or her rights as a participant, the purpose and the method of the study, and the feedback process. The person was then asked to sign a consent form (see Appendix C). Once this was accomplished, the participant and I began the interview process. Interviews were conducted in a private, informal setting in the Schumacher's home or in the home of the participant. This process lasted between two or three hours with most participants and up to five hours with other participants.

The participants were members of the self-help and support group of the Thunder Bay chapter of Ontario Friends of Schizophrenics. Participants were on the average 52 years of age. 26 females and 6 males participated. Generally speaking, most of the female participants were the mothers of people with mental illnesses (see Appendix D). The female bias in the sample reflects the "caregiving" role of many mothers. It was noted that one person in the family assumed responsibility for learning about the illness and caring for the person with schizophrenia. Very often this was a maternal role. A variety of levels of education was noted, with more than 45% of the sample having had at least some university or college training. Twenty-one percent of the sample were retired, while over 45% of the sample were employed, and 18% were full-time volunteers. More than 50% of the sample contributed to the total household income and 34% of the participants' spouses contributed to the household income. 60% of the participants had a monthly income exceeding $1500.00. Most participants (62%) were married and 65% were parents of a person with a mental illness, while 28% were spouses. The characteristics of the sample are presented in Appendix A.

Measures

1. Needs and supports for families and friends. This questionnaire has three major sections which include problem-solving needs and supports, tangible needs and supports, and social-emotional needs and supports. There are six items for the problem-solving and social-emotional needs and supports subscales. There were seven items for tangible needs and supports subscales. The items for the scales were generated by the families of schizophrenics in the Thunder Bay area.

Each of the 19 need items were rated on a three point scale: "not at all," "a little bit," or "quite a bit." The amount of support actually received for each of the 19 needs was also rated on a three point scale: "none at all," "a little bit," or "quite a bit." The services and supports that might have responded to the need were listed and the participants were asked to identify which service or support responded to the need. Two open-ended questions followed. These items asked the participant to first identify issues or concerns about the need and then to provide some suggestions about who might best address the need and how (see Appendix E).

The reliability of this measure was estimated from the internal consistency of the items. The alpha coefficients were found to be significant at the .001 level for: problem-solving needs (.69) and supports (.70), financial and tangible assistance needs (.76) and supports (.74), social-emotional needs (.45) and supports (.84), and for the total degree of need (.81) and supports (.84).

2. Objective burden. The objective burden scale is the modified version of the Family Burden Scale. The modified version developed by Potasznik and Nelson (1984) was an instrument adapted by Test and Stein (1980) from the work of Grad and Sainsbury (1968) (see Appendix F). The scale consists of objective questions which assess the disruption in the household of the family member precipitated by the ex-patient. Participants were asked to rate the frequency of the occurrence of disruptions on a three point scale: "never," "occasionally," or "frequently" a burden. The reliability of this measure was estimated from the internal consistency of the items. The alpha coefficient was found to be .74 in both this study and that of Potasznik and Nelson (1984).

3. PANAS scale. The PANAS Scale was developed and validated by Watson, Clark and Tellegen (1988). It was designed to measure positive

and negative affect which are "two dominant and relatively independent dimensions" (Watson, Clark & Tellegen, 1988). The scale consists of words that describe positive emotions such as interested, excited, strong, enthusiastic, proud, alert, determined, attentive and active, and negative emotions such as distressed, upset, guilty, scared, hostile, irritable, ashamed, nervous, jittery, and afraid. Participants were asked to indicate to what extent they had felt this way during the past few weeks when they thought of the ex-patient. Each emotion was then rated as "very slightly or not at all," "a little," "moderately," "quite a bit," or "extremely." Test-retest reliability was computed for these items and was found to be significant at the .002 level for both positive affect ($\underline{r}$=.88) and for negative affect ($\underline{r}$=.87) (Watson, Clark & Tellegen, 1988) (see Appendix G). The reliability of this measure was estimated from the internal consistency of the items. The alpha coefficient was .77 for positive affect and .90 for negative affect.

Procedure

Various segments of the community were included in the whole process of the study, from the conception and development of the study to the implementation of recommendations resulting from the study. Three segments of the community in Thunder Bay, Ontario were involved in the process of this study: (1) the community at large, (2) persons with a mental illness and family members, and (3) mental health/illness care providers.

Community process. The use of a community process reflected the recognition of the importance of conducting research that is useful and responds to the needs of a particular community. This process involved making use of key informants in the community to determine the issues and concerns in that community. In this study, the researcher met with key informants from agencies involved in the provision and delivery of mental health services.

Key informants included persons from the following agencies: The Thunder Bay District Health Council, The Canadian Mental Health Association (the Executive Director, Director of Action-Rehabilitation Program, Director of Housing, the Director of the Canadian Mental Health Association Clubhouse), the Chief Administrator, the Director of Outpatient Services, the Director of the Social Work Department, the Director of the Homecare Program, and social workers at Lakehead Psychiatric Hospital, persons with schizophrenia, and family members.

The purpose of the meetings with these key informants was to determine the feasibility of conducting a study. Generally speaking, the key informants expressed a concern about the services available for people with schizophrenia living in the city of Thunder Bay. Many persons felt that the needs of the mentally ill and family members were not understood. Based on this community input, a decision was made to conduct a study that would examine the needs of family members of the mentally ill and the degree to which these needs were being met. Other questions of interest were: who (if anyone) currently met these needs, what were the issues and concerns about these needs, and who might best meet these needs and how.

A research advisory committee was formed. The members of this committee included: the Director of the Thunder Bay chapter of Ontario Friends of Schizophrenics (parent), a community health nurse (parent), a professor at Lakehead University and nurse (sibling), a nurse (spouse), the chairperson of the fund-raising committee of the Thunder Bay chapter of Ontario Friends of Schizophrenics (sibling), a person with schizophrenia, and the researcher. The role of this committee was to develop, design and oversee the study. The committee also helped to interpret the results of the study for the community. Other tasks included: the design of the measures, the selection of a pre-test group, the design of a media campaign to alert the community of the study, the selection of a method to report the results to the participants, the design of a workshop, and the preparation of a final report.

Pre-test sessions were held. Each of the participants was interviewed. The purpose of these sessions was to determine if the wording used in the measures was clear and easy to understand. The researcher asked the pre-test participants to comment on the measure and the interview process. A brief report was prepared to report these results. The research advisory committee met to discuss the outcome of the pre-test sessions. A few minor changes were made in the wording of some questions.

Feedback to participants. A feedback session with the participants was held the evening of February 15, 1989. Twenty-six participants attended this meeting. The degree of each need and the degree to which each need was met was presented. The issues and concerns for each, the recommendations about how each need might best be met and by whom, and any other recommendations made by the participants were also presented (see Appendix H). The researcher prepared summary statements of the qualitative data for each need and these were discussed. Participants were asked to determine if these summary statements were accurate. The participants were then given an opportunity to give the researcher feedback on their experience as participants.

Process with community, participants and mental health/illness care providers. The researcher maintained contact with the key informants from January, 1988 until March, 1989. During this period of time, a media campaign was utilized to alert the public to the study and workshop (see Appendix I). Other key informants were recruited during this time. Participants were also informed of the progress of the research.

This process was utilized as a method of bringing together members of the community, persons with a mental illness, family members, and mental health care providers in the city of Thunder Bay. A workshop was proposed as a viable means of bringing these individuals together to discuss the needs of persons with a mental illness and the needs of family members (see Appendix J). The issues and concerns and suggestions made for each need were to be discussed.

Approximately 80 persons attended the workshop. It was held on March 9, 1989, at the Airlane Hotel in Thunder Bay, Ontario. The researcher acted as presenter and facilitator for this one-day workshop. The morning session involved a discussion of the purpose, method, and results of the study. A question period allowed the participants at the workshop to ask questions about this discussion.

During the afternoon, small groups worked together to discuss the practical implications of implementing the recommendations made by the participants in the study. Individuals with a mental illness and family members clarified the need in question and explained the importance of addressing these needs. The individuals from various agencies proposed methods they could employ to implement these changes in their agency. Each need was addressed by a group. A flipchart was used to record the points made during these discussions (see Appendix K). Group facilitators were used to help focus these discussions and to record and report the points discussed.

The participants were asked to complete an evaluation of the workshop (see Appendix L). Twenty-two participants completed the evaluation. Generally, the participants who completed the evaluation found that the workshop was helpful, interesting, and informative. Many persons felt that more time (perhaps one extra day) was needed for this type of workshop.

The mayor of the city, the media, and the federal member of parliament also attended the workshop. Other persons from the community who were not aware of the issues also attended. The use of the workshop as a method of educating people about the needs of the mentally ill and the needs of family members was successful.

Results

Results pertaining to the action-oriented questions of the research are presented first. Next, the results pertaining to the theoretically-oriented questions are presented.

Action-Oriented Questions

There are four action-oriented questions:

1. What are the most important needs of family members?

2. Which of these needs are being met and which are not?

3. What issues and concerns do family members have about how their needs are met?

4. What policy and program suggestions do family members have as to how best to meet their needs?

What follows are results pertaining to these four questions for each of the basic sets of needs that were identified a priori: (1) problem-solving, (2) financial and tangible, and (3) social-emotional.

Total degree of need and supports. The total degree of need and support were computed (see Table 1). There was a greater score for need (54) than for support (31). This shows that there is a discrepancy between the degree of need and the actual support received to meet that need.

Problem-solving needs and supports. At least 85% of the participants felt that there was "quite a bit" of need for problem-solving advice and at least 44% felt that these needs were "not met" (see Table 2). Needs were met by the participants seeking information on their own by at least 25% of participants, by the community support groups for at least 21% of participants, and by the psychiatrist for at least 6% of participants (see Table 3). Issues and concerns, and suggestions made by participants were recorded (see Appendix M). Themes for both issues and concerns and suggestions for changes are summarized in Table 4.

Table 1

Total Degree of Need and Actual Support Received

	Mean score	SD	Possible range
Problem-solving			
Needs	17	1.2	6-18
Supports	10	2.5	
Financial and tangible assistance			
Needs	20	2.3	7-21
Supports	10	2.4	
Social-emotional support			
Needs	17	1.1	6-18
Supports	11	3.4	
Total			
Needs	54	3.2	19-57
Supports	31	6.2	

Table 2

Problem-Solving Needs: The Degree of Need and the Degree of Need Met

	Degree of need (%)			Degree of need met (%)		
	No need	A little	Quite a bit	Need not met	A little	Quite a bit
The need for Information about:						
a) the nature of the illness	0	0	100	0	56	44
b) the medications, their effects and side effects	0	6	94	44	47	9
c) how to handle symptomatic behaviour	0	12	88	50	31	19
d) limitations due to the illness	0	9	91	53	37	10
e) level of motivation due to illness	3	9	88	50	47	3
f) community resources	0	15	85	50	44	6

Note: These values represent the percentage of responses made by participants.

Table 3

Supports Used to Meet Specific Problem-Solving Needs

	Problem Solving Needs (%)					
Supports	Nature of the illness	Information on medications	Advice on behaviour	Advice on limitations	Advice on level of motivation	Information on community resources
a) myself	81	44	28	25	28	31
b) spouse	15	6	6	6	0	6
c) nuclear family	9	6	9	6	6	3
d) extended family	9	0	6	6	0	3
e) CMHA*	12	6	3	9	0	9
f) a friend	13	3	6	6	3	0
g) physician	28	13	9	3	0	3
h) community support group	75	13	28	16	13	22

(table continues)

	Problem-Solving Needs (.)					
Supports	Nature of the illness	Information on medications	Advice on behaviour	Advice on limitations	Advice on level of motivation	Information on community resources
i) hospital support group	31	3	3	6	6	9
j) nurse	3	6	3	0	0	3
k) social worker	16	3	6	13	9	16
l) pharmacist	0	6	0	0	0	0
m) psychologist	16	0	0	3	6	0
n) psychiatrist	41	13	6	16	13	13
o) patient advocate	3	0	0	0	0	3
p) outpatient services	9	0	0	0	3	3
q) other hospital staff	0	0	0	0	0	0

(table continues)

Supports	Problem-solving needs (%)					
	Nature of the illness	Information on medications	Advice on behaviour	Advice on limitations	Advice on level of motivation	Information on community resources
r) community mental health worker	0	0	0	0	0	0
s) other**	19	3	3	0	0	0

* CMHA: Canadian Mental Health Association

** here other was the media, television, radio, pamphlets, books, etc.

Note: These values represent the percentage of responses made by participants.

Table 4

Themes for Issues and Concerns, and Suggestions for Problem-Solving Needs

A. These are the issues and concerns about meeting the need for information about:

1. The nature of the disorder. As family members, people need to understand as much as they can about behaviour and symptoms. First hand experience from other family members is very helpful. Family members often have to search for information on their own. Information is not readily available and it is not always accurate.

Doctors and psychiatrists don't seem to understand the illness. Doctors and psychiatrists have very little time for the person with a mental illness and for family members.

2. Medications, their effects and side effects. Families want to know all they can about medications, their effects and side effects so that they can understand the effects of the medications on the person's behaviour and be able to recognize side effects. Families are not given this information and must look for it on their own.

The person with a mental illness must be told why the medication has been prescribed, why he or she must continue to take this medication, and what effects the medications may have.

3. How to handle symptomatic behaviour. There is a gap in service at the community level. There is a need for a crisis center in the community. People should not be picked up by the police or brought to hospital.

(table continues)

Family members feel that they need to learn how to help the person.

Family members want to be referred to self-help and support groups. Self-help and support organizations should advertise and provide information about the role of their organization.

4. Limitations due to the illness. Family members need this information so that their expectations take into account the effects of the illness on the person. This information must also be taught to professionals so that they can pass it on to family members.

5. Motivation levels due to the illness. Family members and mental health professionals need to understand the effects of the illness and medications on the person's level of motivation.

The importance of self-help and support groups and community-based services must be recognized.

6. Community resources available for people with a mental illness. Family members feel that they need this information. This information should not be given in "bits and pieces." Community-based programs must be tailored to meet the needs of the mentally ill. Self-help and support groups are valuable resources and should be recognized as such.

B. These are suggestions about how to meet the need for information about:

1. The nature of the disorder. Professionals who work with persons with a mental illness must be educated about the nature of the illness, the effects of the illness on the person and the family, the effects of medications, and how to make use of a team approach to help

(table continues)

people with a mental illness and their families.

Persons with the illness and family members want to be included in the development of the treatment plan and in the selection of appropriate referrals.

People with a mental illness and their families need immediate referral to self-help groups, support groups, and to hospital education programs. All mental health professionals should be aware of the value of these services and they should ensure that their clients are told of them.

Public education about mental illness and the experience of mental illness is essential. The media should be used in a variety of ways to attain this goal.

2. Medications, their effects and side effects. When prescriptions for medications are made or changed, the person (doctor of psychiatrist) who prescribes the medication should inform the individual and interested family members about: why the medication was prescribed, the dosage, the side effects, long-term effects, effects on behaviour, effect when alcohol is consumed, the degree of impairment due to the medication, and the effects of the medication on the individual's ability, aptitude, and mood.

Whenever possible, the patient should be told of LPH's Form 14. They have the option to sign this form if they want family members to be included in the treatment plan.

As with other illnesses, individuals who take medication must receive some follow-up while they are taking this medication to

(table continues)

determine if: medications are effective, dosage is accurate, side effects are adverse, and medication or dosage should be changed.

3. How to handle symptomatic behaviour. Doctors, psychiatrists, mental health professionals, and family members need to learn how to deal with behaviours that are attributed to mental illness and medications.

The municipal and provincial police forces, nurses, emergency room hospital staff, and general practitioners also need to be taught how to recognize symptomatic behaviour and how to help the individual.

Some methods that were recommended to teach people how to handle symptomatic behaviour include: making use of the persons with a mental illness to teach others about what is best for them at times of crisis, counselling for family members with role-playing, and making use of support groups where families can share their experiences and learn from each other.

4. Limitations due to the illness. Persons with a mental illness and family members want education programs that offer practical alternatives and suggestions about what the limitations of the illness are, and how to help the individual cope with these limitations.

Persons with a mental illness need community-based rehabilitation programs that take into account the level of the illness and the individual's

personality, abilities and aptitudes. This program should focus on individual need, and take into account personality differences, and promote ability and individuality.

5. Motivation levels due to the illness. Mentally ill persons and

(table continues)

family members want referrals to trained mental health professionals who can help them understand and cope with the effects of the illness and medications on the individual's level of motivation.

6. Community resources available for people with a mental illness. A directory must be created. This directory should include: a list of all agencies that provide services to individuals with a mental illness, a description of the role of each agency, the method of referral to the agency, the name of a contact person for each agency, and the location and telephone number of each agency. This directory should be updated once a year.

Trained mental health professionals should be available to work with persons with a mental illness and their families on an on-going basis. The emphasis should be meeting the needs of the person. Mental health/illness workers should: act as a resource for information, provide assistance to the treatment team, act as an advocate for the person, and provide counselling and support for the person and for family members.

24-hour assistance is needed for persons with a mental illness and their families during times of crisis.

Financial and tangible assistance needs. At least 48% of participants felt that there was "quite a bit" of need for financial and tangible assistance and at least 38% felt that these needs were "not met" (see Table 5). At least 56% of the participants stated that the disability pension program provided financial assistance to the mentally ill person, and 28% stated that Employment and Immigration Canada

(Canada Employment Center) provided education (see Table 6). Issues and concerns, and suggestions for change made by participants were recorded (see Appendix N). Themes for both issues and concerns, and suggestions were summarized in Table 7.

Social-emotional needs and supports. At least 91% of participants felt that there was "quite a bit" of need for social-emotional support and at least 22% felt that these needs were "not met" (see Table 8). The community support group met these needs for at least 12% of participants, while nuclear family members met these needs for at least 15%, and spouses for at least 12% of participants (see Table 9). Issues and concerns, and suggestions for changes made by participants were recorded (see Appendix O). Themes for both issues and concerns, and suggestions were summarized in Table 10.

Other themes. Other common themes did not respond to any specific needs that were examined in the study. The issues and concerns, and suggestions based on these themes are summarized in Table 11. Common themes included: amendments to the Mental Health Act, creation of a drop-in centre, need for mental health/illness workers, changes of policy on loss of pension and/or housing, need for advocate/resource personnel, formation of a "youth" group, making use of the mentally ill as resources, recognizing the value of self-help and support groups, creation of a media campaign, ensuring accuracy of literature, distinguishing between mental health the mental illness, cooperative efforts between hospital and community, increased funding, and program evaluation of community-based services.

Table 5

Financial and Tangible Assistance Needs: The Degree of Need and the Degree of Need Met

The need for:	Degree of need (%)			Degree of need met (%)		
	No need	A little	Quite a bit	Need not met	A little bit	Quite a bit
a) housing	3	6	91	63	34	3
b) education	6	6	88	63	28	9
c) employment	0	6	94	66	32	2
d) financial assistance	0	0	100	38	56	6
e) community follow-up	12	15	73	68	19	13
f) help with money management	13	9	78	69	25	6
g) respite services or care	0	52	48	88	10	2

Note: These values represent the percentage of responses made by participants.

Table 6

Supports Used to Meet Specific Financial and Tangible Assistance Needs

Supports	Financial and tangible assistance needs (%)						
	Housing	Education	Employment	Financial assistance	Follow-up	Money management	Respite services
a) myself	6	0	6	6	3	3	6
b) spouse	6	0	3	3	0	0	6
c) nuclear family	0	0	3	0	0	3	6
d) extended family	6	0	3	0	0	3	6
e) CMHA*	3	0	9	0	3	6	0
f) a friend	0	0	0	0	3	0	0
g) physician	3	0	3	0	0	0	0
h) community support group	3	0	0	0	0	0	0

(table continues)

Financial and tangible assistance needs (%)

Supports	Housing	Education	Employment	Financial assistance	Follow-up	Money management	Respite services
i) hospital support group	0	0	0	3	0	0	0
j) nurse	0	0	0	0	0	0	0
k) social worker	6	3	6	6	0	0	0
l) pharmacist	0	0	0	0	0	0	0
m) psychologist	0	0	0	0	0	0	0
n) psychiatrist	6	0	6	0	0	3	0
o) patient advocate	0	0	0	0	0	0	0
p) outpatient services	0	3	0	0	0	0	0
q) other hospital staff**	0	3	6	0	3	3	1
r) community mental health worker	0	0	0	0	0	0	0

(table continues)

Financial and tangible assistance needs (%)

Supports	Housing	Education	Employment	Financial assistance	Follow-up	Money management	Respite services
s) other***	19	28	19	57	13	9	3

* CMHA: Canadian Mental Health Association

** here other hospital staff were occupational therapists

*** other: for housing: subsidized housing or supervised accommodations

for education: use of Employment and Immigration training programs

for employment: use of Employment and Immigration employment programs

for financial assistance: disability pension

for money management: Lutheran services

Note: These values represent the percentage of responses made by participants.

Table 7

Themes for Issues and Concerns, and Suggestions for Financial And Tangible Assistance Needs

A. These are the issues and concerns about meeting the need for:

1. Housing. Family members cannot be responsible for providing housing (in their home) for the person with a mental illness, or for paying their rent. The mentally ill person needs his/her privacy, but support is also needed so that the person does not isolate him/herself.

2. Education. Two key elements must be considered when education programs are designed for persons with a mental illness. First, these programs should attempt to meet the needs of the person. Second, the person's goals, aptitudes and abilities must be considered when these programs are designed.

3. Employment. Employment opportunities are important as employment fosters feelings of productivity. People with a mental illness should be given the opportunity to perform various types of tasks (not just menial tasks) and employment opportunities should give them an opportunity to focus on their abilities.

4. Financial assistance. People with a mental illness, as a group, are especially vulnerable to the effects of stress and poor nutrition that often result from insufficient financial assistance. Just because a person has a mental illness does not mean that they should live at a marginal level or be welfare recipients. Parents and family members should not be responsible for providing financial support.

(table continues)

5. Community follow-up. Parents and family members provide much of the follow-up and support needed by people with a mental illness. This is a conflicting role for them. It is a conflicting role because parents are pulled in to provide parental nurturance and support to an adult, and because they provide support and care that mental health professionals should provide. Community-based services based on the degree of need should be available.

6. Help with money management. Spending habits may often be a manifestation of the illness. Also, because the onset of the illness often occurs during young adulthood, they often do not learn how to manage money. Parents should not be responsible for "holding the purse strings" as this is a conflicting role for them.

7. Respite services or care. The experience of mental illness is stressful for all family members. The person and family members feel that they need a break from one another from time to time. One key element would be that the person with a mental illness feel comfortable with any arrangements made for respite services.

B. These are suggestions about how to meet the need for:

1. Housing. There is a need for housing which would be designed to meet the needs of people with a mental illness. Geared to income, housing must be increased and diversified. Many individuals are able to live in the community with some support from mental health professionals and appropriate housing.

2. Education. Education programs should be based on individual aptitude, ability and need.

(table continues)

Vocational/rehabilitation programs should be community-based and should address goals outlined by the individual and his/her mental/illness worker.

Education programs should be conducted by trained teachers or mental health professionals who recognize the effects of the illness and medications, and stress experienced by the person with a mental illness.

3. Employment. Supportive employment programs must be created. These programs should involve: education of employers, training of the individual, support for the individual, and a consideration of the aptitudes and abilities of the individual.

4. Financial assistance. The application for the disability pension should be facilitated by mental health professionals who assist individuals by: providing information about the pension, assisting the individual to apply for the pension, and assisting the individual to obtain medical certificates.

The amount of money of the disability pension must be increased so that individuals can afford: food, clothing, and housing. Presently the amount of the disability pension does not cover the costs of basic needs of a person, nor does it allow the individual to have some spending money for recreation and/or savings. The amount of the pension must be scaled to the cost of living. Individuals with a mental illness should not have to live at a marginal level because they have a mental illness.

5. Community follow-up. People with a mental illness need community follow-up so that they can live independently. Follow-up

(table continues)

programs should be flexible so that as the individual's needs change, more or less support would be provided.

Programs such as Meals on Wheels and Homecare were recommended.

6. Help with money management. Trained mental health/illness workers should be available to help people with mental illness with money management. It should be recognized that it is difficult to budget for expenses when the amount of the pension is inadequate.

Doctors, psychiatrists, and mental health professionals need to recognize that spending habits may be a manifestation of the illness.

7. Respite services or care. Persons with a mental illness, adult family members, and children do need respite services. Suggestions to meet this need have included retreat and follow-up during family absences.

Many family members felt that the hospital should be used to provide respite care. It was noted that none of the individuals with the illness felt that this was a viable alternative.

Table 8

Social-Emotional Support Needs: The Degree of Need and the Degree of Need Met

The need for:	Degree of need ( )			Degree of need met ( )		
	No need	A little	Quite a bit	Need not met	A little bit	Quite a bit
a) continued support	0	6	94	22	50	23
b) acknowledgement of family contribution	0	6	94	50	28	22
c) relief from guilt or worry	0	0	100	35	44	21
d) addressing future concerns	3	3	94	44	31	25
e) expressed interest and concern	0	9	91	28	47	25
f) on-going emotional support	0	6	94	28	41	31

Note: These values represent the percentage of responses made by participants.

Table 9

Supports Used to Meet Specific Social-Emotional Support Needs

	Social-emotional support needs (%)					
Supports	Continued support	Aknowledgement of support	Relief from guilt/worry	Future concerns	Expressed interest and concern	Availability of support
a) myself	6	0	3	3	3	3
b) spouse	22	13	25	16	19	19
c) nuclear family	31	16	25	31	38	34
d) extended family	16	6	16	16	22	19
e) CMHA*	3	3	3	6	3	6
f) a friend	6	22	35	31	31	34
g) physician	44	3	3	6	6	3
h) community support group	13	19	28	28	41	34

(table continues)

Supports	Social-emotional support needs (%)					
	Continued support	Acknowledgement of support	Relief from guilt/worry	Future concerns	Expressed interest and concern	Availability of support
i) hospital support group	3	0	3	3	0	3
j) nurse	9	0	0	0	0	0
k) social worker	0	16	13	0	6	9
l) pharmacist	0	0	0	0	0	0
m) psychologist	3	6	0	0	0	0
n) psychiatrist	0	13	6	6	3	9
o) patient advocate	0	0	0	0	0	0
p) outpatient services	0	0	0	0	0	0
q) other hospital staff	0	0	0	0	0	0
r) community mental health worker	0	0	0	0	0	0
s) other	0	0	0	0	0	0

* CMHA: Canadian Mental Health Association

Note: These values represent the percentage of responses made by participants.

Table 10

Themes for Issues and Concerns, and Suggestions for Social-Emotional Support Needs

A. These are the issues and concerns about meeting the need for:

1. Continued support. Family members feel that they are alone, that no one is available, and that there will be no on-going support after the person is discharged from the hospital. Having someone to talk with is important, therefore, the support of a spouse, other family members and friends is needed.

2. Acknowledgement of family contribution. Family members make a valuable contribution to the support and care of the person. Many professionals do not acknowledge this contribution and do not accept the valuable input that family members want to provide.

3. Relief from guilt or worry. Family members need to talk. They feel that referrals to self-help and support groups and to mental health professionals would give them the opportunity to voice some of their concerns and to learn more about the illness and its effects.

4. Addressing concerns about the future. Family members provide much support and care for the person with a mental illness. They worry about what will happen to that person when they are no longer able to provide this assistance. Family members need to feel that there is hope for something better for the person.

5. Expressed interest and concern. Family members often feel very alone because: other family members are insensitive; people ignore the person and the illness; there is a stigma attached to the illness; and

(table continues)

the general public does not understand mental illness. An expression of sensitivity to the feelings of the person and family members is needed.

6. On-going emotional support. Family members need to know that there is someone available to talk with. Referrals to self-help and support groups and trained social workers would be helpful.

B. These are suggestions about how to meet the need for:

1. Continued support. People with a mental illness and their families need emotional support. Immediate referral to self-help and support groups would address this need in part. Trained doctors, psychiatrists, and mental health professionals who understand this need would be helpful as these persons could then provide emotional support.

People with a mental illness and their families have recommended that public education might address their need for emotional support. Education would decrease the stigma of mental illness and open a variety of channels for communication and support.

2. Acknowledgement of family contribution. The contribution that family members make in terms of financial, tangible, social, and emotional support must be recognized by doctors, psychiatrists and mental health professionals. Family members must be recognized as credible sources and must be included in the treatment plan.

Individuals with a mental illness also want to have input in the treatment plan. Treatment plans should focus on the person's needs.

3. Relief from guilt or worry. Doctors, psychiatrists and mental health professionals must be educated about the nature of the illness so that family members are not blamed for the illness.

(table continues)

Family members want to receive a wide variety of education so that they can address the needs of the person in appropriate ways. Knowing how to help the person will decrease their feelings of guilt or worry.

4. Addressing concerns about the future. Persons with a mental illness,and their families, recognize that the manifestation of the illness changes over time. They worry about what will happen to the ill person in the future. They recommend that we address issues such as on-going support in the community, housing and financial assistance so that the care of the person will be assured in the future. Family members need to have access to a trained lawyer who would help them prepare their wills so that they can make provisions for the person.

5. Expressed interest and concern. Persons with a mental illness need social and emotional support. At this time, they are receiving little or no support aside from the support received from family members. Trained mental health professionals who would understand their concerns would be helpful. An educated public would improve the situation as people with a mental illness might then be treated with respect, compassion, and understanding.

6. On-going emotional support. Persons with a mental illness and family members need trained mental health professionals who understand the illness and the effects of the illness on people's lives. They need someone they can call on for advice, counselling, and support.

The value of self-help and support groups must be recognized by doctors, psychiatrists, and mental health professionals. Each client can be referred to the self-help and support group.

Table 11

Other Themes

A. Amendments to the Mental Health Act.

1. The confidentiality issue must be examined as professionals often use it to exclude family members from the treatment plan. Those who suggested this were participants wanting their family included in the treatment plan or family members of a person with a mental illness and the person wanted his/her family included in the treatment plan.

2. The Act often prevents the person with a mental illness from receiving prompt treatment at time of crisis. The current procedure requires people to first see a Justice of the Peace, then the person with a mental illness must be classified as being a danger to him/herself or others now or in the future. This is a painful process for the person and for family members.

B. Creation of a drop-in centre. This facility could be separate from the crisis centre or part of it. People need a place to go on a 24-hour basis. They should not have to be "in crisis" to have access to this type of facility. Because of the manifestation of the illness, this facility should be open all night as this is when people may use it most. This facility should be created for both the person and for their families.

C. Need for mental health/illness workers. Mental health/illness workers are needed. These individuals should be trained specifically to work with people with a mental illness. They should be taught about the nature of

(table continues)

the illness, medications, motivation factors, how to handle the illness, and available community resources. They should also be aware of the financial, tangible, social, and emotional needs of the persos with a mental illness and of family members. They must be able to work on a one-to-one basis with the person and be prepared to provide support and reassurance. They must be available for several sessions per week and be prepared to go into the community to the mentally ill person.

D. Change of policy on loss of pension and/or housing. Persons with a mental illness should not lose their disability pension or their housing because they are in the hospital. The reality of mental illness is that the person will at some time or another be admitted to the hospital. Services such as housing programs and pension plans should incorporate "rules" that take into account the illness. At this time, these policies are being challenged and changed. The results of this study support these changes.

E. Need for advocate/resource personnel. It was suggested that members of the police force, firemen and general hospital staff have someone they can contact if they believe a person with a mental illness is in their custody or care. An advocate/resource person should be available on a 24-hour basis. This individual could work out of a community-based drop-in centre. The responsibilities of this position should include: answering calls and questions, discerning whether or not the individual in question has a mental illness, instructing callers about an appropriate course of action, going to the police station or hospital, advocating for the person, and facilitating access to crisis

(table continues)

services for people with a mental illness.

F. Formation of a "youth" group. The formation of a "youth" group is vital and necessary. The membership of this "youth" group should include: persons under the age of 45, persons with a mental illness, persons without a mental illness, family members, spouses and concerned/interested citizens. The functions of this group would be to: decrease isolation, have "fun" activities, informal gatherings, special events, and to provide an opportunity for people to meet others. People with a mental illness want to have contact with persons other than family members. They want to have the opportunity to develop relationships and to relate with persons who do not have a mental illness. It should not be assumed that the experience of mental illness is similar for all persons. There are different levels of the illness. Also, it should not be assumed that the people with a mental illness only want to relate with other people with a mental illness. Individuality, personality, aptitude, ability, preferences, dislikes and qualities are unique to each person, whether or not he/she has a mental illness.

G. Making use of the mentally ill as resources. Individuals with a mental illness want to be used as resources to professionals, family members and the community. They have expressed a need to share their experience of the illness with people who want to know about mental illness and its effects on people's lives. Family members and professionals need this information; people with a mental illness are excellent resources for this information.

(table continues)

Persons with a mental illness do not want to be isolated from the community. They do not want to be feared and ridiculed. Some want to contribute by being volunteers in community agencies. This would allow them to participate in a productive way in community life. This may also help decrease or eradicate the stigma associated with mental illness, the general population would then have contact with people with a mental illness.

H. Recognizing the value of self-help and support groups. The value of self-help and support groups must be recognized. The groups provide emotional support, information, and practical advice to the mentally ill and their families. Doctors, psychiatrists and professionals must recognize these groups as valuable resources for their patients/clients.

These groups have played and continue to play a vital role in the city of Thunder Bay. The primary mandate of these groups is to act as advocates, sponsor research and lobby for change. At this time, they perform a variety of tasks beyond their mandate. When appropriate services are developed and implemented, these groups will then be able to fulfill their mandate.

I. Creation of a media campaign. A nation-wide media campaign is needed. The purpose of this campaign should be to decrease the stigma of mental illness and to educate the public.

People with a mental illness, family members, mental health professionals, the medical community, and a renowned spokesperson should be selected to address the issues of mental illness, to disseminate

(table continues)

information and to challenge the myths and stereotypes associated with mental illness. Mental illness as a "taboo" of our society must be challenged. Television, radio, and the press should be used to access the public.

J. Ensuring accuracy of literature. Secondary school, college, university, hospital and public libraries should be given a list of accurate and up-to-date literature on mental illness. At this time, many inaccurate sources are circulating. The circulations of these sources contributes to the misunderstanding of the illness.

K. Distinguishing between mental health and mental illness. A distinction must be made between mental health and mental illness. These two concepts are often misused, substituted, or misunderstood. Mental health is a concept that defines the emotional health of a person. Stress, diet and exercise are key components of mental health.

Mental illness is an illness. It attacks the brain and has adverse effects on behaviour. The symptoms include: mania, depression, delusions, and/or hallucinations. It must be treated with medication. It usually affects a person for the rest of his/her life.

The mental health of people with a mental illness is a concept that has not been addressed. Here we are concerned with the emotional health of a person with a mental illness. Many of the same prerequisites for mental health of the mentally ill and mental health of the general population apply. Feeling productive and valued, having enough money for food and a decent place to live, not being isolated from others, having family and friends, exercise, and stress contribute to the mental health of everyone.

(table continues)

L. Cooperative efforts between hospital and community. The psychiatrists, doctors, nurses, social workers and psychologists must be aware of what is happening at the community level. At this time, cooperative efforts have begun. Hospital staff must be given information about the needs of people with a mental illness and their families. Persons with a mental illness, family members and community-based agency personnel must share information about needs and resources with hospital staff and hospital staff must do the same in return. The Ontario hospital is part of the community, it is an "institution" within the community. Community members and hospital staff must work together to break existing "barriers."

M. Increase funding. Funding must be increased for all agencies that provide services for individuals with a mental illness. The suggestions and recommendations are in place. Money is now needed to develop, expand, and implement appropriate services.

N. Program evaluation of community-based services. Feasibility studies should be conducted to determine the feasibility of evaluating these services. Program evaluation from a consumer perspective must be conducted to determine if the services meet the needs of the mentally ill. The mentally ill and family members feel that many existing services do not meet the needs of those who make use of the services and that the mandate of the services does not reflect an understanding of the illness or the needs of the mentally ill.

Summary. Family members experienced a significant degree of need in all need categories. Some of the needs were met, but for the majority of participants, attempts to meet their needs were largely due to efforts made on their own part. Participants had very definite and clear issues and concerns for each of the needs. Concrete suggestions were made about how needs might best be met and by whom. Participants also highlighted other themes that must be addressed in order to meet needs, and suggestions about how to address these themes were made.

Intercorrelations of Measures

Prior to performing the analyses pertaining to the three theoretical questions, the distribution of scores on the burden and affect measures was examined. These distributions are presented in Appendices P and Q. Also, the intercorrelations of the independent variables and the intercorrelations of the dependent variables were examined before the major analyses were performed.

The intercorrelations of the need and support measures are presented in Table 12. Scores for the specific need subscales were all highly correlated with the Total Need score. Similarly, scores for the specific support subscales were all highly significantly correlated with the Total Support score. The various support subscales were moderately intercorrelated with one another. While Problem-Solving and Social-Emotional needs were intercorrelated, neither of these subscales were significantly correlated with Financial and Tangible Assistance Needs.

The intercorrelations of the measures of burden and affect are presented in Table 13. Negative Affect was significantly correlated with Objective Burden, but Positive Affect was not significantly correlated with either of the other two measures.

Table 12

Correlations Between Need and Support Measures

Types of needs and supports	Problem-solving		Financial and tangible		Social-emotional		Total	
	Needs	Supports	Needs	Supports	Needs	Supports	Needs	Supports
Problem-solving								
needs	1.00							
supports	.07	1.00						
Financial and tangible								
needs	.21	.16	1.00					
supports	.19	.42**	.44**	1.00				
Social-emotional								
needs	.76*	.13	.19	.18	1.00			
supports	.06	.28	-.17	.40**	.01	1.00		
Total								
need	.67**	.12	.85**	.43**	.63**	-.09	1.00	
supports	.07	.70**	.14	.76*	.14	.81**	.16	1.00

* $p < .05$

** $p < .01$

Table 13

Correlations Between Measures of Burden and Affect

	Mean score	SD	Objective burden	Positive affect	Negative affect
Objective Burden	10.9	1.8	1.00		
Positive Affect	30.2	7.6	-.25	1.00	
Negative Affect	26.4	10.5	.34*	-.15	1.00

*p<.05

The intercorrelations for need and support measures and measures of Objective Burden, Positive Affect and Negative Affect are presented in Table 14.

Theoretical Questions

Question #1. Is there a relationship between problem-solving, financial and tangible assistance, and social-emotional needs and objective burden, negative affect, and positive affect? The Financial and Tangible Assistance Needs subscale and the Total Needs score were significantly correlated with Objective Burden (see Table 14). None of the other correlations between the need measures and the dependent variables were significant.

Question #2. Is there a relationship between the receipt of problem-solving, financial and tangible, and social-emotional supports and objective burden, negative affect, and positive affect? There were significant relationships between Social-Emotional Supports and the dependent variables. Objective Burden was significantly negatively correlated with Social-Emotional Supports, as was Negative Affect (see Table 14). Positive Affect was significantly correlated with Social-Emotional Supports. The Total Supports score was significantly inversely correlated with Negative Affect.

Question #3. Is there an interaction between needs and supports? Will needs and supports interact to predict objective burden, negative affect, and positive affect in accordance with the stress-buffering hypothesis? Multiple regression analyses were performed. Financial and Tangible Assistance Needs and Supports interacted to predict Objective Burden (see Table 15). This interaction was graphed and was not found to conform to a stress-buffering effect. Analyses to predict Negative Affect showed that no significant interactions between needs and supports (see Table 16). Problem-Solving, Financial and Tangible Assistance, and Social-Emotional Needs and Supports did not interact to predict Positive Affect (see Table 17).

Summary. Financial and Tangible Assistance Needs and Total Needs were positively correlated with Objective Burden, while Social-emotional Supports were negatively correlated with Objective Burden and Negative Affect. Social-emotional Supports were positively correlated with Positive Affect. The Total Support Score was negatively correlated with Negative Affect.

It would appear that the experience of burden by family members of the mentally ill is closely tied to needs for support in financial assistance, housing education, employment opportunities, community follow-up, help with money management and respite services or care. The amount of social-emotional support received seems to be related to the

Table 14

Correlations Between Need and Support Measures and Measures of Objective Burden, Positive Affect and Negative Affect

	Dependent variables		
Independent variables	Objective burden	Positive affect	Negative affect
Problem-Solving			
Needs	.07	-.01	-.10
Supports	.25	.22	-.10
Financial and Tangible Assistance			
Needs	.46*	.03	-.04
Supports	.16	.04	-.29
Social-Emotional			
Needs	.10	.04	.09
Supports	-.34*	.38*	-.51**
Total Scores			
Needs	.33*	.02	-.04
Supports	.04	.27	-.43*

*p<.05

**p<.01

degree of Objective Burden, Negative Affect and Positive Affect experienced. Support for all needs appears to be related to positive feelings by family members, yet it does not interact with support to predict Objective Burden, Negative Affect or Positive Affect. Needs and supports for Financial and Tangible Assistance did interact to predict Objective Burden, but not in a way that was consistent with the stress-buffering hypothesis.

Table 15

Hierarchical Regression of Needs and Supports on Objective Burden

Criterion	Predictors	Beta	Statistics
Objective burden	Problem-solving needs	-.232	t(30) = -.30
	Problem-solving supports	-.887	t(30) = -.36
	Interaction	1.116	t(30) = .47
	Total		F(3,28) = .737
Objective burden	Financial and tangible assistance needs	-2.161	t(30) = -2.41
	Financial and tangible assistance supports	-6.731	t(30) = -2.83*
	Interaction	8.162	t(30) = 2.84*
	Total		F(3,28)= 4.179*
Objective burden	Social-emotional needs	-.006	t(30) = -.01
	Social-emotional supports	-.783	t(30) = -.11
	Interaction	.463	t(30) = .066
	Total		F(3,28)= 1.216

(table continues)

Criterion	Predictors	Beta	Statistics
Objective burden	Total needs	-2.388	$t(30) = -1.61$
	Total supports	-9.764	$t(30) = -1.85$
	Interaction	10.460	$t(30) = 1.83$
	Total		$F(3,28) = 2.176$

* $p<.01$

** $p<.05$

Table 16

Hierarchical Regression of Needs and Supports on Negative Affect

Criterion	Predictors	Beta	Statistics
Negative affect	Problem-solving needs	-.753	$t(30) = -.96$
	Problem-solving supports	2.772	$t(30) = -1.13$
	Interaction	2.557	$t(30) = 1.07$
	Total		$F(3,28) = .706$
Negative affect	Financial and tangible assistance needs	-1.948	$t(30) = -2.01$
	Financial and tangible assistance supports	-5.517	$t(30) = -2.14$
	Interaction	6.368	$t(30) = 2.04$
	Total		$F(3,28) = 2.197$
Negative affect	Social-emotional needs	9.985	$t(30) = 2.12$**
	Social-emotional supports	-10.779	$t(30) = 1.75$
	Interaction	9.985	$t(30) = -1.83$
	Total		$F(3,28) = 5.904$*

(table continues)

Criterion	Predictors	Beta	Statistics
Negative affect	Total needs	-.940	$t(30)$ = -.67
	Total supports	3.580	$t(30)$ = -.62
	Interaction	3.669	$t(30)$ = -.61
	Total		$F(3,28)$ = 1.519

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* $p<.01$

** $p<.05$

Table 17

Hierarchical Regression of Needs and Supports on Positive Affect

Criterion	Predictors	Beta	Statistics
Positive affect	Problem-solving needs	.645	*t*(30) = .86
	Problem-solving supports	2.625	*t*(30) = 1.09
	Interaction	-2.356	*t*(30) = -1.00
	Total		*F*(3,28) = .964
Positive affect	Financial and tangible assistance needs	.939	*t*(30) = .88
	Financial and tangible assistance supports	2.332	*t*(30) = .83
	Interaction	-2.929	*t*(30) = -.86
	Total		*F*(3,28) = .302
Positive affect	Social-emotional needs	-1.676	*t*(30) = -1.31
	Social-emotional supports	-7.143	*t*(30) = -1.10
	Interaction	7.738	*t*(30) = 1.15
	Total		*F*(3,28) = 2.377

(table continues)

Criterion	Predictors	Beta	Statistics
Positive affect	Total needs	1.111	$t(30) = .70$
	Total supports	4.383	$t(30) = .77$
	Interaction	-4.490	$t(30) = -.73$
	Total		$F(3,28) = .684$

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* $p<.01$

** $p<.05$

Discussion

Practical and Theoretical Perspectives on the Needs of Family Members of the Mentally Ill

The concept of action-oriented research is based on the ecological metaphor and approach to community psychology (Trickett, 1984). An examination of the needs of families of people with schizophrenia, and attempts to match these needs with resources, promotes the concept that there should be an optimal "fit" between the person and the environment. Action-oriented strategies in research were used to achieve an overall perspective of the needs of families of people with schizophrenia, the degree to which these needs are met, the issues and concerns families have about their needs, and suggestions about how policies and programs should be changed in order to match family needs and community resources.

Other researchers have noted some of the needs family members of people with a mental illness (Hatfield, 1978; Geist, 1985; St. Onge & Lavoie, 1987). A classification of the needs into categories for needs and supports provided a framework for the study of a wide variety of needs. Problem-solving, financial and tangible assistance, and social-emotional needs and supports provided a means of examining groups of needs, allowed participants to discuss issues and concerns, and provided suggestions for individual needs and for categories of need. This framework was also helpful as family members were able to generate themes that were not related to specific needs but to categories of need.

The increased responsibility for caring for mentally ill family members due to deinstitutionalization has resulted in an interest in the family experience. This has prompted researchers to examine the experience of burden of family members of individuals with a mental illness (Potasznik & Nelson, 1984). Independent dimensions of affect are also seen as an important aspect of the experience of family members. Action-oriented strategies and theoretical perspectives of burden, affect, and the needs of family members of persons with a mental illness do foster a better understanding of the family experience. Positive Affect included emotions such as interested, excited, strong, enthusiastic, proud, alert, determined, attentive, and active. Negative Affect included emotions such as distressed, upset, guilty, scared, hostile, irritable, ashamed, nervous, jittery, and afraid. Each approach provides different types of results. Both approaches and their respective results are examined here. Implications from these results and suggestions for future research are discussed.

Perspectives on action-oriented results and strategies for change. There were five types of questions in the action-oriented aspect of this study. They included: needs, supports, who provides support, issues and concerns, and suggestions. Each of these areas are reviewed for each of the three categories of need. Other themes highlighted by family members are discussed. Some effects that resulted from action-oriented strategies are discussed.

The degree of need experienced by family members surpassed the amount of support they received across all need categories. The greatest problem-solving needs were the need for information about: the nature of the illness, medications, their effect and side effects, and limitations due to the illness. Almost half of the participants felt that there was no support to meet these needs. Other researchers have reported similar findings for information needs (St. Onge & Lavoie, 1984) and for support needs (Appleton, 1974; Marcus, 1977; Abramowitz & Coursey, 1989). In order to meet their needs, family members attempted to find information on their own, with the help of a community support or self-help group, or with the help of a psychiatrist. Other researchers have noted this trend (St. Onge & Lavoie, 1984; Potasznik & Nelson, 1984).

Family members discussed issues and concerns for problem-solving needs and generated suggestions about who might best meet their needs and how. They felt that they needed education programs for themselves and for professionals. At this time, many people still have unrealistic ideas and inaccurate information about schizophrenia; education would help remedy this problem. Education should focus on a variety of aspects of mental illness. Referrals to self-help and support groups, including the mentally ill person in the treatment plan, and providing services at the community level would also be helpful in providing support for problem-solving needs.

Family-oriented psychoeducational interventions have been developed (Abramowitz & Coursey, 1989). This form of intervention focuses on education and support rather than family therapeutic issues. The emphasis is on helping families deal with mental illness by building on their strengths by providing knowledge and information. The successful programs focus on an understanding of the illness and medications, appropriate expectations and management of the person with schizophrenia, and information on community resources (Abramowitz & Coursey, 1989). This type of psychoeducational program would meet the need for problem-solving support. Educational programs should focus on meeting these specific needs.

Financial assistance, employment, and housing needs were not met for more than half of the family members. These findings are supported by other researchers who found that there were needs for financial assistance (Potasznik & Nelson, 1984), for employment (St. Onge & Lavoie, 1984), and for housing (Leaf, 1977; Thompson & Doll, 1982). In order to meet their needs, family members stated that their mentally ill relative made use of the Disability Pension program to meet some financial need, supervised accommodations or subsidized housing programs to meet housing needs, and government programs to meet employment needs. The main issues and concerns for these needs and supports centered on the fact that these programs should be tailored to meet the needs of people with a mental illness. Often, the mentally ill person would lose his or her disability pension, subsidized or supervised housing, or position in an employment program if he or she was admitted to hospital. Family members suggested that programs be created to meet the needs of the person. It was also noted that when the ill person experienced difficulties in obtaining financial and tangible assistance, the person experienced additional stress and this stress sometimes contributed to the illness by exacerbating symptoms. As a result, family members also experienced stressful situations.

Family members expressed a great deal of need for all types of social-emotional support. These needs included the need for continued support, acknowledgement of family contribution, relief from guilt or worry, addressing concerns about the future, expressed interest and concern, and on-going emotional support. Support for family contribution to the needs of persons with a mental illness was not met for half of the family members. This finding is supported by other research (Appleton, 1974; Hatfield, 1978; Geist, 1985). Professionals must begin to acknowledge family contribution. It was suggested that family members be included in the treatment plan as they are often key resources for the person. Concerns about the future of the person with a mental illness must also be considered. Trained lawyers and social workers must acknowledge this need and help families plan for the care of the person in the event of the death of family members.

Family members do receive some social-emotional support from informal networks such as spouses, friends, and self-help and support groups. Issues and concerns focused on support from professionals. The trend in current research supports the need for recognition of these needs by professionals (Grad & Sainsbury, 1968; Marcus, 1977).

The development of programs and policy should be based on a recognition of family need. Researchers have begun to realize that a clear understanding of family needs should be an integral part of program and policy development (Anderson, 1977; Marcus, 1977; Geist, 1985). Family members outlined a variety of suggestions based on themes related to their needs. These themes included: amendments to the Mental Health Act, creation of a drop-in centre, the need for mental health/illness workers, change of policy on loss of pension and/or housing, the need for advocate/resource personnel, formation of a "youth" group, making use of people with a mental illness as a resource, recognition of the value of self-help and support groups, creation of a media campaign, ensuring accuracy of literature, distinguishing between mental health and mental illness, cooperative efforts between hospital and community, increased funding, and program evaluation of community-based services. Family members had clear and concise suggestions about how these themes should be addressed.

One method to address all needs, issues, concerns and suggestions was to address and inform other family members, individuals with a mental illness, and professionals about needs. This was achieved by conducting a workshop, in which the results of this study were presented. Small groups of family members and persons with a mental illness persons discussed these needs with professionals. Together they outlined the practical implications of applying the suggestions in various agencies. Several committees were formed to address groups of needs. Professionals, family members, and persons with a mental illness volunteered to be members. At this time their work continues.

The workshop was a successful method of sharing the results of the study, talking with professionals about how to tailor programs to meet need and to assess impact of the study on the community. The attendance rate reflected a vested interest on the part of professionals. The attendance of the media and politicians also increased the impact of the study on the community. "Credible" sources reported and discussed the needs of people with schizophrenia in Thunder Bay. Some of the changes that resulted from the workshop included: recruitment of younger people, increasing membership of tyhe Association, educating professionals, public education and increased awareness, and impact on the attitudes of professionals on the needs of people with a mental illness.

At this time the Public Relations Committee continues to recruit new members for the Association. This recruiting process has three functions. First, attempts are made to reach more family members in need of support and education. Second, efforts are made to bring in new members who may not know about mental illness. Finally, increased membership results in increased funding. This allows the Association to become involved in new projects.

The Education Committee is currently undertaking another research project in conjunction with the Canadian Mental Health Association. The purpose of this study is to design an education program similar to the program at Mohawk College in Hamilton, Ontario. The program will provide some vocational and rehabilitation components, but will focus on providing support and education tailored to the needs of people with schizophrenia.

Action-oriented strategies to collect quantitative and qualitative information were useful in this research. Family need and supports were readily discerned in the context of the family and community. The use of action-oriented stratgies also had theoretical implications for community psychology.

<u>Theoretical perspectives on the study of needs, supports, burden, and affect</u>. Action-oriented strategies and naturalistic methods of study do enable researchers to examine theoretical questions. In this study three questions were examined. First, the relationships between

needs, and objective burden, negative affect, and positive affect were examined. Second, the relationships between supports and objective burden, negative affect, and positive affect were examined. Finally, analyses to determine if needs and supports interacted to predict objective burden, negative affect, and/or positive affect. Other theoretical questions involved an examination of the independence of positive and negative affect and the "stress-buffering" hypothesis.

Researchers have examined the level of objective burden experienced by family members of the mentally ill (Platt & Hirsch, 1981; Potasznik & Nelson, 1984; Platt, 1985). Some researchers have discussed the role of self-help and support groups and how these groups provide support to family members (Biegel & Yamatani, 1986; Drescher, 1986). Until now, the needs and supports of family members of people with a mental illness have not been systematically examined. Nelson's (1987) framework for categorizing needs and supports provided a "good fit" for the study of need and provided a theoretical framework that was practical.

In the past, researchers have focused on the results of measures of subjective burden in order to understand the affective experience of family members (Test & Stein, 1980). Unfortunately, measures of subjective burden examine only negative emotions toward the person with a mental illness. The absence of negative emotion does not ensure positive emotion and the reverse is also true. Therefore, both positive and negative affect are separate and independent variables that should be examined.

The first question involved in determining whether or not there was a relationship between needs, and objective burden, negative affect and positive affect. The degree of need for financial and tangible assistance and the total degree of need for problem-solving, financial and tangible assistance, and the social-emotional needs were related to the degree of objective burden experienced by family members. This finding is supported by other research (Platt & Hirsch, 1981). What is clear is that family members experience an increase in household disruption when they are also in need of financial and tangible assistance. As a result, they may be providing financial assistance and housing and they may not be receiving help in other categories of need, and this contributes to the overall experience of burden.

The fact that problem-solving and social-emotional needs alone were not related to objective burden indicates that neither of these categories alone are related to disruption in the home. It should be noted that financial and tangible assistance needs are related to tangible types of disruptions that can be measured in terms of the effect on the household. It might then be expected that "non"-tangible needs would be related to "non"-tangible experiences such as positive and/or negative affect. The results did not support this hypothesis as problem-solving and social-emotional needs were not related to negative affect or positive affect. This could be due to a "ceiling effect," as needs were rated as "high" across all need categories.

The second question was to determine the relationship between different supports and objective burden, negative affect, and positive affect. Objective burden and negative affect were related to the amount of social-emotional support received. The nature of these relationships provides insight. When there is little social-emotional support, high degrees of objective burden and negative affect are experienced by family members. Professionals can play a significant role if they attempt to reach family members at a social-emotional level. Providing social-emotional support may prove to be most beneficial to family members. Mental health professionals need to "reframe" their approach. Family members not only need social-emotional support, they also need to feel that there is hope for change or for something better for the person. The scope of intervention should be broadened so that people with schizophrenia and family members are helped by mental health professionals who understand the illness and the impact on the family, and who will help decrease the experience of family burden. One way of expanding the role would be to have mental health professionals who act as facilitators to help link people to support networks. As a result, this type of service provision to family members might in turn be a provision of service to the person with schizophrenia as family members would be better equipped to help their kin with a mental illness. Provincial and federal agencies need to recognize that these services are vital and, that as with any other illness, services pertaining to illness should be funded by the government.

The degree of social-emotional support is also related to positive affect. With social-emotional supports in place, family members experience greater positive affect. Thus, when a spouse, friends, family members, or professionals provide social-emotional support, family members experience positive affect. Feelings such as interest, excitement, strength, pride, enthusiasm, alertness, inspiration, determination, attentiveness, and/or activity can be emotions associated with or felt for the person with a mental illness.

When supports are not in place for problem-solving, financial and tangible assistance, and social-emotional needs, negative affect increases. But feeling distressed, upset, guilty, scared, hostile, irritable, ashamed, nervous, jittery, and/or afraid will decrease when supports are in place. It should be noted that support for all need categories must be in place for this of occur.

A third question or hypothesis examined the interaction between need and support as predictors of objective burden, negative affect, and positive affect. Again the indirect model or the "stress-buffering" hypothesis was examined. Need and support for financial and tangible assistance interacted to predict objective burden. Needs and supports did not interact to predict either positive or negative affect. This is not surprising as positive affect is not a contributing factor to stress.

Negative aspects of well-being can be predicted as support will decrease negative experience and this also supports the "stress buffering" hypothesis. The fact that need and support do not interact to predict positive affect does not refute the indirect mode. Negative and positive affect are separate and independent. Well-being involves both negative and positive affect. Until now, well-being has been considered the absence of negative and the presence of positive affect (Bradburn, 1969). Perhaps well-being should be considered in terms of the degree of each type of affect experienced versus the presence of one and the absence of the other.

Cohen and Wills (1985) discussed an indirect or "stress-buffering" model of well-being and support. They proposed that support acts as a buffer and protects persons from stressful events. With this model, increased support would be related to decreased objective burden and negative affect. It would not be related to positive affect, because positive emotion is not related to stress. Family members who receive little or no problem-solving, financial and tangible assistance, and social-emotional support also experience greater objective burden and negative affect.

In practical terms, the experience of positive feelings toward the person with a mental illness, with little or no support and negative feeling would be a "normal" response. Family members may feel discouraged or upset but they still experience positive emotions toward their relative with a mental illness. As a result, there may be more household disruptions. Increased objective burden would then reflect the family's attempts to meet the needs of the mentally ill person. In attempting to meet these needs, negative affect, positive affect, and objective burden may be experienced simultaneously.

Theoretical perspectives for community psychology. The ecological perspective proposed by Mills and Kelly (1972) is a realistic method for examining the needs of family members of people with a mental illness. Attempts can be made to direct community resources to address the problems. The ecological metaphor (Trickett, 1984), research relationships, and action-oriented strategies reflect this paradigm.

The ecological metaphor proposed by Trickett (1984) contributed to the success of this study. Ex-patients, family members, professors, and professionals helped design the study and the measures. "Ownership' for

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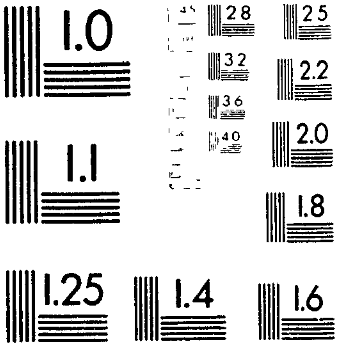

the study belonged to the advisory committee and the participants. This "ownership" was affirmed repeatedly as their input and feedback was used at all stages of the study. Members of the faculty at Lakehead University became interested in the results and recommendations of the study. Several members of the advisory committee and the researcher were asked to speak with university and college students about the research.

Community "ownership" was also an underlying issue at the local and provincial level. Professionals had an opportunity to meet with the advisory committee and the researcher at several stages throughout the process of the study. The Director of the local Chapter of Ontario Friends of Schizophrenics was asked to share the final report with the provincial representatives of the association. A media campaign was a useful method of ensuring public awareness of the study and results. The campaign resulted in an increase in membership for the local self-help and support group and in an increase of donations. The workshop for ex-patients, family members, citizens, and professionals served as an added method to increase public knowledge and awareness about mental illness, to recruit volunteers, and to secure provincial and federal funding.

Action-oriented strategies such as those discussed by Heller et al. (1984) are useful. The researcher is able to determine the "facts" from the perspective of people who experience the effects of mental illness. Lewin (1951) supports this "fact finding" as a method of research; he also promotes "evaluation." In this study, "evaluation" began to occur at the workshop. The practical implications of applying suggested changes to existing community agencies and to programs at Lakehead Psychiatric Hospital were discussed. Also, several committees were formed to work on ensuring that the changes are implemented.

Evaluation is also occurring at this time as a new research project was undertaken recently. Funding was secured to allow the education committee to hire staff to assist them. This study will look at education needs. The goal is to design a college program for people with a mental illness (this program will be similar to the program at Mohawk College, but will be tailored to need).

Summary

Action-oriented strategies are a successful means of "fact finding." In this study, family members of persons with a mental illness were able to discuss their needs, supports, who has met their needs, issues and concerns, and suggestions about who might best meet their needs and how.

Objective burden, negative affect, and positive affect were examined. Needs for financial and tangible assistance and total needs were related to the degree of objective burden experienced by family members. Social-emotional support was negatively related to negative affect and objective burden, and positively related to positive affect. Negative affect and positive affect appear to be separate and independent factors contributing to well-being.

Community psychology provides theory and promotes research in community settings. Trickett's (1984) ecological metaphor and Lewin's (1951) theory of "fact finding" and "evaluation" serve as successful guides for community research and for fostering community change.

Conclusion

Family members of people with schizophrenia find themselves having to provide care and support for their mentally ill kin. Because family members take on this responsibility, they experience a variety of needs. In the past, family members have often been blamed for the illness and have had to struggle on their own with little or no help or support. Some family members have made use of self-help and support groups as a forum where they could discuss their needs and receive support.

The needs of family members fall into three categories: problem-solving, financial and tangible assistance, and social-emotional needs. The total degree of need was related to the experience of burden. Thus, disruption of domestic routine was related to the degree of need experienced. Financial and tangible assistance needs were also related to burden. The degree of support was also related to objective burden and negative affect for social-emotional support. The less support received, the greater the experience of burden and negative affect. On the other hand, increased social-emotional support was related to increased positive affect. The need for financial and tangible assistance and support interacted to predict objective burden and social-emotional needs and support interacted to predict negative affect. It was clear that the degree of need, the degree of support, objective burden, negative affect, and positive affect could be examined in a meaningful framework that provided a better understanding of the family experience.

This framework allowed the researcher to examine categories of needs and supports. The results indicated that when categories of need were met with appropriate support, objective burden and negative affect would decrease and positive affect would increase. Theoretically speaking, if programs and policy were tailored to meet specific needs by providing support, family members would have a greater sense of well-being. This was clearly an example of providing an optimal "fit" between the needs of a group of citizens and community resources.

Other theoretical conclusions concerned affect and stress. The experience of family members of the mentally ill clearly supported the theory that negative and positive affect were independent of each other. While family members did experience negative affect, the capacity and experience of positive affect was also evident.

Future research and community efforts should focus on tailoring programs to meet the needs of ex-patients and/or family members. This might involve evaluating existing programs to provide an optimal "fit" between needs and resources. If new programs and policies will be successful, family members and ex-patients must be used as resources in any design or implementation of change.

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Appendix A

Demographic Data of Family Members

	Number	%
Number of Participants	32	
Sex: male	6	18.8
female	26	81.3
Work Status		
part-time student	1	3.1
part-time work	1	3.1
part-time volunteer	0	0
full-time work	10	31.3
full-time volunteer	6	18.8
full-time work at home	5	15.6
unemployed	1	3.1
retired	7	21.9
Sources of Income in Household		
employment	18	56.3
spouse's employment	11	34.4
unemployment insurance	3	9.4
social insurance	1	3.1
other	9	28.1

	Number	%
Household Monthly Income		
$000.- 250.	1	3.1
250.- 500.	1	3.1
500.- 750.	3	9.4
750.-1000.	2	6.3
1000.-1250.	0	0
1250.-1500.	7	21.9
1500.-1750.	2	6.3
1750.-2000.	0	0
2000.-2250.	3	9.4
2250.-2500.	1	3.1
2500.-2750.	3	9.4
2750.-3000.	3	9.4
3000.-	3	9.4
Marital Status		
single	0	0
married	20	62.5
separated or divorced	5	15.6
widowed	7	21.9
Education Level		
partial high school	6	18.8
high school graduate	10	31.3
some university or college	5	15.6

	Number	%
community college certificate	5	15.6
university degree	5	15.6
graduate or professional training	1	3.1
Relationship to the Person with the Illness		
parent	21	65.6
sibling	1	3.1
niece or nephew	1	3.1
spouse	9	28.1

Appendix B

Objective and Method of the Study and Outline of Rights of Participants

Needs, Supports, and Burden: The Experience of Family Members of Individuals with Mental Illness

Objectives of the study.

1. To determine support needs of the psychiatrically disabled and their families from their own perspective.

2. To determine gaps in agencies' support services for the psychiatrically disabled and their families.

3. To develop recommendations describing how agencies can improve their support services.

4. To develop potential strategies to improve their support services based on strategies that can be used by the psychiatrically disabled and their families.

5. To bring together the psychiatrically disabled and their families to share research and to develop a future plan of action.

Method.

Families will be interviewed. The questions selected for the interview were based on needs identified by family members.

The purpose of the interview is to identify needs, whether or not these needs have been met, who (if anyone) has met these needs, the issues and concerns about these needs, and suggestions about who might best meet these needs and how

As participants, you will also be asked to participate in the interpretation of results and the formulation of recommendations. The results and the recommendations made will be presented in an open workshop sometime in January, 1989.

<u>Rights</u>.

As a participant, you have the following rights:

1. Informed consent: the right to be fully informed about the purpose and requirements of the study before consenting to be involved.

2. Confidentiality: the right to have all information kept private and in the strictest confidence. No one's name will be associated with any of the information they provide.

Appendix C

Informed Consent Form

September, 1988

I, ______________________________, agree to participate in the study of Needs, Supports, and Burden: The Experiences of Family Members of Individuals with Mental Illness by Lysanne Chenier-Chretien and Dr. G. Nelson of Wilfrid Laurier University, Department of Psychology, with the Family and Friends of Schizophrenics Association and the Self-Help and Support Group for Manic Depressives.

I have been informed of my rights as a participant. I am aware of the procedure that will be followed.

____

Date: ________________________

Appendix D

Demographic Data Information Sheet

Demographic Information

1. Name ____________________________________

2. Age ____________

3. Address ____

4. Phone number ______________________

5. Sex _________ Male

   _________ Female

6. Work Status

   ______ part-time student

   ______ part-time volunteer work

   ______ part-time work

   ______ full-time work

   ______ full-time volunteer work

   ______ full-time work at home

   ______ unemployed

   ______ other (specify ______________________________)

7. Sources of Income (check more than one if applicable)

   ______ employment

   ______ spouse's employment

   ______ U.I.C.

   ______ pension

   ______ social insurance

   ______ other (specify ______________________________)

8. Gross Monthly Income (all sources)

____ $ 0-$250
____ 250- 500
____ 500- 750
____ 750-1000
____ $1,000-$1,250
____ 1,250- 1,500
____ 1,500- 1,750
____ 1,750- 2,000
____ $2,000-$2,250
____ 2,250- 2,500
____ 2,500- 2,750
____ 2,750- 3,000
____ >3,000

9. Marital Status

______ Single
______ Married
______ Separated or Divorced
______ Widowed

Appendix E

Measure of Support and Service for Families and Friends

Support and Service for Families and Friends

I. Advice and practical help

A. Information about the disorder.

1. How much information do you think you and your family need about the nature of the disorder (e.g., what it is, symptoms, onset, prognosis, etc.)?

(a) none at all
(b) a little bit
(c) quite a bit

2. How much information about the nature of the disorder have you and your family actually received?

(a) none at all
(b) a little bit
(c) quite a bit

3. What services or supports have helped you and your family's need for information about the nature of the disorder?

(a) myself
(b) spouse
(c) nuclear family members
(d) extended family members
(e) Canadian Mental Health Association
(f) a friend
(g) physician
(h) community support group

(i) hospital support group

(j) nurse

(k) social worker

(l) pharmacist

(m) psychologist

(n) psychiataist

(o) patient advocate

(p) outpatient services

(q) other hospital staff (please specify __________)

(r) community health worker

(s) other (please specify ________________________)

4. What issues or concerns do you have about the information family members receive about the nature of the disorder? (Was the information useful or useless? Was it helpful or harmful?)

5. What suggestions to you have to better meet the information needs of family members about the nature of the disorder? Who and how?

B. Medication and effects (regarding information about medications, their effects and side effects).

1. How much information do you think you and your family need about medications, their effects and side effects?

(a) none at all
(b) a little bit
(c) quite a bit

2. How much information about medications, their effects and side effects have you and your family actually received?

(a) none at all
(b) a little bit
(c) quite a bit

3. What services or supports have given you and your family information about medications, their effects and side effects?

(a) spouse
(b) family members
(c) physician
(d) Canadian Mental Health Association
(e) a friend
(f) community support group
(g) hospital support group
(h) nurse
(i) social worker
(j) pharmacist
(k) psychologist
(l) psychiatrist

(m) patient advocate

(n) outpatient services

(o) other hospital staff (please specify __________)

(p) community mental health worker

(q) other (please specify ______________________)

4. What issues or concerns do you have about the information family members receive about medications, their effects and side effects? (Was the information useful or useless? Was it helpful or harmful?)

5. What suggestions do you have to better meet the information needs of family members regarding medications, their effects? Who and how?

C. Behaviour (advice on how to deal with the person when he/she becomes disturbed or symptomatic).

1. How much information do you think you and your family need about how to deal with the person when he/she becomes disturbed or symptomatic?

(a) none at all
(b) a little bit
(c) quite a bit

2. How much information about how to deal with the person when he/she becomes disturbed or symptomtic have you and your family actually received?

(a) none at all
(b) a little bit
(c) quite a bit

3. What services or supports have helped you and your family's information needs on how to deal with the person when he/she becomes disturbed or symptomatic?

(a) spouse
(b) family members
(c) physician
(d) Canadian Mental Health Association
(e) a friend
(f) community support group
(g) hospital support group
(h) nurse
(i) social worker

(j) pharmacist

(k) psychologist

(l) psychiatrist

(m) patient advocate

(n) outpatient services

(o) other hospital staff (please specify __________)

(p) community mental health worker

(q) other (please specify ________________________)

4. What issues or concerns do you have about the information family members receive about how to deal with the person when he/she becomes disturbed or symptomatic?

5. What suggestions do you have to better meet the information needs of family members on how to deal with the person when he/she becomes disturbed or symptomatic?

D. Limitations on persons with psychiatric illnesses (advice on what to reasonably expect the person to be able to do).

1. How much information do you and your family need about what to reasonably expect the person to be able to do?

(a) none at all

(b) a little bit

(c) quite a bit

2. How much information have you actually received about what to reasonably expect the person to be able to do?

(a) none at all

(b) a little bit

(c) quite a bit

3. What services or supports have helped you and your family's needs regarding what to reasonably expect the person to be able to do?

(a) spouse

(b) family members

(c) physician

(d) Canadian Mental Health Association

(e) a friend

(f) community support group

(g) hospital support group

(h) nurse

(i) social worker

(j) pharmacist

(k) psychologist

(l) psychiatrist

(m) patient advocate

(n) outpatient services

(o) other hospital staff (please specify __________)

(p) community mental health worker

(q) other (please specify _________________________)

4. What issues or concerns do you have about the information family members receive about what to reasonably expect the person to be able to do? (Was it useful or useless? Was it helpful or harmful?)

5. What suggestions do you have to better meet the information needs of family members on what to reasonably expect the person to be able to do? Who and how?

E. Level of motivation (advice on dealing with the person's level of motivation).

1. How much information do you and your family need about dealing with the person's level of motivation?

(a) none at all
(b) a little bit
(c) quite a bit

2. How much information about dealing with the person's level of motivation have you and your family actually received?

(a) none at all
(b) a little bit
(c) quite a bit

3. What services or supports have helped you and your family's information needs about dealing with the person's level of motivation?

(a) spouse
(b) family members
(c) physician
(d) Canadian Mental Health Association
(e) a friend
(f) community support group
(g) hospital support group
(h) nurse
(i) social worker
(j) pharmacist
(k) psychologist
(l) psychiatrist

(m) patient advocate

(n) outpatient services

(o) other hospital staff (please specify __________)

(p) community mental health worker

(q) other (please specify ________________________)

4. What issues or concerns do you have about the information family members receive about dealing with the person's level of motivation?

5. What suggestions do you have to better meet the information needs of family members about dealing with the person's level of motivation? Who and how?

F. Community resources (information on what services or community resources are available for the person).

1. How much information do you and your family need on what services or community resources are available for the person?

(a) none at all

(b) a little bit

(c) quite a bit

2. How much information on what services or community resources for the person have you and your family actually received?

(a) none at all

(b) a little bit

(c) quite a bit

3. What services or supports have helped you and your family's needs regarding information on what services or community resources are available for the person?

(a) spouse

(b) family members

(c) physician

(d) Canadian Mental Health Association

(e) a friend

(f) community support group

(g) hospital support group

(h) nurse

(i) social worker

(j) pharmacist

(k) psychologist

(l) psychiatrist

(m) patient advocate

(n) outpatient services

(o) other hospital staff (please specify __________)

(p) community mental health worker

(q) other (please specify ______________________)

4. What issues or concerns do you have about the information family members receive on what services or community resources are available for the person?

5. What suggestions do you have to better meet the information needs of family members on what services or community resources are available for the person?

II. Financial and tangible assistance

Regarding sharing the responsibilities for caring for and supporting the person:

A. Housing (appropriate housing for the person based on his/her needs).

1. How much do you think you and your family need appropriate housing for the person?

(a) not at all
(b) a little bit
(c) quite a bit

2. How much have you and your family actually received appropriate housing for the person?

(a) not at all
(b) a little bit
(c) quite a bit

3. What services or supports have helped you and your family's need for appropriate housing for the person?

(a) spouse
(b) family members
(c) physician
(d) Canadian Mental Health Association
(e) a friend
(f) community support group
(g) hospital support group
(h) nurse
(i) social worker

(j) pharmacist

(k) psychologist

(l) psychiatrist

(m) patient advocate

(n) outpatient services

(o) other hospital staff (please specify __________)

(p) community mental health worker

(q) other (please specify ________________________)

4. What issues or concerns do you have about appropriate housing for the person?

5. What suggestions do you have to better appropriate housing for the person?

B-1 Education (education opportunities for the person).

1. How much do you think you and your family need educational opportunities for the person?

(a) not at all

(b) a little bit

(c) quite a bit

2. How much have you and your family actually received educational opportunities for the person?

(a) not at all

(b) a little bit

(c) quite a bit

3. What services or supports have helped you and your family's need for educational opportunities for the person?

(a) spouse

(b) family members

(c) physician

(d) Canadian Mental Health Association

(e) a friend

(f) community support group

(g) hospital support group

(h) nurse

(i) social worker

(j) pharmacist

(k) psychologist

(l) psychiatrist

(m) patient advocate

(n) outpatient services

(o) other hospital staff (please specify __________)

(p) community mental health worker

(q) other (please specify _________________________)

4. What issues or concerns do you have about educational opportunities for the person?

5. What suggestions do you have to better educational opportunities for the person? Who and how?

B-2 Employment (supportive employment for the person).

1. How much do you think you and your family need educational opportunities for the person?

(a) not at all

(b) a little bit

(c) quite a bit

2. How much have you and your family actually received supportive employment for the person?

(a) not at all

(b) a little bit

(c) quite a bit

3. What services or supports have helped you and your family's need for supportive employment for the person?

(a) spouse

(b) family members

(c) physician

(d) Canadian Mental Health Association

(e) a friend

(f) community support group

(g) hospital support group

(h) nurse

(i) social worker

(j) pharmacist

(k) psychologist

(l) psychiatrist

(m) patient advocate

(n) outpatient services

(o) other hospital staff (please specify __________)

(p) community mental health worker

(q) other (please specify _________________________)

4. What issues or concerns do you have about supportive employment for the person?

5. What suggestions do you have to better supportive employment opportunities for the person? Who and how?

C. Financial assistance (financial assistance to help the person cope with their disability).

1. How much do you think you and your family need financial assistance to help the person cope with his/her disability?

(a) not at all
(b) a little bit
(c) quite a bit

2. How much have you and your family actually received financial assistance to help the person cope with his/her disability?

(a) not at all
(b) a little bit
(c) quite a bit

3. What services or supports have helped you and your family's need for financial assistance to help the person cope with his/her disability?

(a) spouse
(b) family members
(c) physician
(d) Canadian Mental Health Association
(e) a friend
(f) community support group
(g) hospital support group
(h) nurse
(i) social worker
(j) pharmacist
(k) psychologist

(l) psychiatrist

(m) patient advocate

(n) outpatient services

(o) other hospital staff (please specify __________)

(p) community mental health worker

(q) other (please specify ________________________)

4. What issues or concerns do you have about financial assistance to help the person cope with his/her disability?

5. What suggestions do you have to better financial assistance to help the person cope with his/her disability?

D. Follow-up - community resources (some support from outside the family to help the person with meals and household chores).

1. How much support from outside the family do you think you and your family need to help the person with meals and household chores?

(a) none at all

(b) a little bit

(c) quite a bit

2. How much support from outside the family have you and your family actually received to help the person with meals and household chores?

(a) none at all

(b) a little bit

(c) quite a bit

3. What services or supports have helped you and your family's need for some support from outside the family to help the person with meals and household chores?

(a) spouse

(b) family members

(c) physician

(d) Canadian Mental Health Association

(e) a friend

(f) community support group

(g) hospital support group

(h) nurse

(i) social worker

(j) pharmacist

(k) psychologist

(l) psychiatrist

(m) patient advocate

(n) outpatient services

(o) other hospital staff (please specify __________)

(p) community mental health worker

(q) other (please specify ________________ __________)

4. What issues or concerns do you have about support from outside the family to help the person with meals and household chores?

5. What suggestions do you have to better support from outside the family to help the person with meals and household chores?

E. Money management (some support from outside the family to help the person with money management).

1. How much do you think you and your family need some support from outside the family to help the person with money management?

(a) not at all

(b) a little bit

(c) quite a bit

2. How much have you and your family actually received support from outside the family to help the person with money management?

(a) not at all

(b) a little bit

(c) quite a bit

3. What services or supports have helped you and your family's need for some support from outside the family to help the person with money management?

(a) spouse

(b) family members

(c) physician

(d) Canadian Mental Health Association

(e) a friend

(f) community support group

(g) hospital support group

(h) nurse

(i) social worker

(j) pharmacist

(k) psychologist

(l) psychiatrist

(m) patient advocate

(n) outpatient services

(o) other hospital staff (please specify __________)

(p) community mental health worker

(q) other (please specify _________________________)

4. What issues or concerns do you have about support from outside the family to help the person with money management?

5. What suggestions do you have to better support from outside the family to help the person with money management? Who and how?

F. Respite services or care (some support from outside the family so that the person and the family get a break from one another).

1. How much do you think you and your family need some support from outside the family so that the person and the family get a break from one another?

(a) not at all
(b) a little bit
(c) quite a bit

2. How much have you and your family actually received support from outside the family so that the person and the family get a break from one another?

(a) not at all
(b) a little bit
(c) quite a bit

3. What services or supports have helped you and your family's need for some support from outside the family so that the person and the family get a break from one another?

(a) spouse
(b) family members
(c) physician
(d) Canadian Mental Health Association
(e) a friend
(f) community support group
(g) hospital support group
(h) nurse
(i) social worker

(j) pharmacist

(k) psychologist

(l) psychiatrist

(m) patient advocate

(n) outpatient services

(o) other hospital staff (please specify ___________)

(p) community mental health worker

(q) other (please specify __________________________)

4. What issues or concerns do you have about support from outside the family so that the person and the family get a break from one another?

5. What suggestions do you have to better support from outside the family so that the person and the family get a break from one another?

III. Help for families and friends

Emotional support with respect to feelings experienced regarding the person:

A. Continued support (someone to talk with when you feel frustrated or angry about the person).

1. How much do you think you and your family need someone to talk with when you feel frustrated or angry about the person?

   (a) not at all
   (b) a little bit
   (c) quite a bit

2. How much have you and your family actually received support from someone to talk with when you feel frustrated or angry about the person?

   (a) not at all
   (b) a little bit
   (c) quite a bit

3. What services or supports have helped you and your family's need for someone to talk with when you feel frustrated or angry about the person?

   (a) spouse
   (b) family members
   (c) physician
   (d) Canadian Mental Health Association
   (e) a friend
   (f) community support group
   (g) hospital support group

(h) nurse

(i) social worker

(j) pharmacist

(k) psychologist

(l) psychiatrist

(m) patient advocate

(n) outpatient services

(o) other hospital staff (please specify __________)

(p) community mental health worker

(q) other (please specify ________________________)

4. What issues or concerns do you have about having someone to talk with when you feel frustrated or angry about the person?

5. What suggestions do you have to better support from someone you may talk with when you feel frustrated or angry about the person?

B. Acknowledgement of support (someone to acknowledge and compliment you on how helpful you have been to the person).

1. How much do you think you and your family need someone to acknowledge and compliment you on how helpful you have been to the person?

(a) not at all
(b) a little bit
(c) quite a bit

2. How much have you and your family actually had someone to acknowledge and compliment you on how helpful you have been to the person?

(a) not at all
(b) a little bit
(c) quite a bit

3. What services or supports have helped you and your family's need for someone to talk with when you feel frustrated or angry about the person?

(a) spouse
(b) family members
(c) physician
(d) Canadian Mental Health Association
(e) a friend
(f) community support group
(g) hospital support group
(h) nurse
(i) social worker

(j) pharmacist

(k) psychologist

(l) psychiatrist

(m) patient advocate

(n) outpatient services

(o) other hospital staff (please specify __________)

(p) community mental health worker

(q) other (please specify ________________________)

4. What issues or concerns do you have about having someone to acknowledge and compliment you on how helpful you have been to the person?

5. What suggestions do you have to better support from someone to acknowledge and compliment on how helpful you have been to the person?

C. Relief from guilt or worry (someone to talk with when you feel guilty or worried about the person).

1. How much do you think you and your family need someone to talk with when you feel guilty or worried about the person?

(a) not at all
(b) a little bit
(c) quite a bit

2. How much have you and your family actually had someone to talk with when you feel guilty or worried about the person?

(a) not at all
(b) a little bit
(c) quite a bit

3. What services or supports have helped you and your family's need for someone to talk with when you feel guilty or worried about the person?

(a) spouse
(b) family members
(c) physician
(d) Canadian Mental Health Association
(e) a friend
(f) community support group
(g) hospital support group
(h) nurse
(i) social worker
(j) pharmacist
(k) psychologist

(l) psychiatrist

(m) patient advocate

(n) outpatient services

(o) other hospital staff (please specify __________)

(p) community mental health worker

(q) other (please specify ________________________)

4. What issues or concerns do you have about having someone to talk with when you feel guilty or worried about the person?

5. What suggestions do you have to better support from someone to talk with when you feel guilty of worried about the person?

D. Future concerns (someone to talk with when you are worried about the future of person).

1. How much do you think you and your family need someone to talk with when you are worried about the future of the person?

(a) not at all

(b) a little bit

(c) quite a bit

2. How much have you and your family actually had someone to talk with when you are worried about the future of the person?

(a) not at all

(b) a little bit

(c) quite a bit

3. What services or supports have helped you and your family's need for someone to talk with when you are worried about the future of the person?

(a) spouse

(b) family members

(c) physician

(d) Canadian Mental Health Association

(e) a friend

(f) community support group

(g) hospital support group

(h) nurse

(i) social worker

(j) pharmacist

(k) psychologist

(l) psychiatrist

(m) patient advocate

(n) outpatient services

(o) other hospital staff (please specify __________)

(p) community mental health worker

(q) other (please specify __________________________)

4. What issues or concerns do you have about having someone to talk with when you are worried about the future of the person?

5. What suggestions do you have to better support for you when you are worried about the future of the person?

E. Expressed interest and concern (someone to express interest and concern in the well-being of the person).

1. How much do you think you and your family need someone to express interest and concern in the well-being of the person?

(a) not at all

(b) a little bit

(c) quite a bit

2. How much have you and your family actually had someone express interest and concern in the well-being of the person?

(a) not at all

(b) a little bit

(c) quite a bit

3. What services or supports have helped you and your family's need for someone to express interest and concern in the well-being of the person?

(a) spouse

(b) family members

(c) physician

(d) Canadian Mental Health Association

(e) a friend

(f) community support group

(g) hospital support group

(h) nurse

(i) social worker

(j) pharmacist

(k) psychologist

(l) psychiatrist

(m) patient advocate

(n) outpatient services

(o) other hospital staff (please specify ________)

(p) community mental health worker

(q) other (please specify ______________________)

4. What issues or concerns do you have about having someone express interest and concern in the well-being of the person?

5. What suggestions do you have to increase interest and concern in the well-being of the person?

F. Availability of support (someone who allows you to confide your concerns about the person).

1. How much do you think you and your family need someone who allows you to confide your concerns about the person?

(a) not at all

(b) a little bit

(c) quite a bit

2. How much have you and your family actually had someone who allows you to confide your concerns about the person?

(a) not at all

(b) a little bit

(c) quite a bit

3. What services or supports have helped you and your family's need for someone who allows you to confide your concerns about the person?

(a) spouse

(b) family members

(c) physician

(d) Canadian Mental Health Association

(e) a friend

(f) community support group

(g) hospital support group

(h) nurse

(i) social worker

(j) pharmacist

(k) psychologist

(l) psychiatrist

(m) patient advocate

(n) outpatient services

(o) other hospital staff (please specify __________)

(p) community mental health worker

(q) other (please specify ________________________)

4. What issues or concerns do you have about having someone who allows you to confide your concerns about the person?

5. What suggestions do you have to better support for you when you need someone to confide your concerns about the person?

Appendix F

Objective Burden Scale

Stress for Families and Friends

Instructions: Please circle the letter on the scale which best describes how often these events occur.

1. How often have you or any other member of your household missed work due to the person?

(a) frequently

(b) occasionally

(c) never

2. How often has any member of this household stayed away from school due to the person?

(a) frequently

(b) occasionally

(c) never

3. How often have your social and leisure activities, or those of any other member been disrupted or different from usual in any way because of the person? (e.g., Have you gone out less often than usual, or have you had to change plans at the last minute?).

(a) frequently

(b) occasionally

(c) never

4. How often has there been any occasion when your usual housework or domestic routine, or that of any other member of your household has been upset because of the person? For instance, has anyone had to set things aside, or do them at a different time than they

had planned or preferred to? Have you or any other household member been unable to get as much housework done as you usually do?

(a) frequently

(b) occasionally

(c) never

5. How often has any member of this household had difficulties with the neighbors because of the person? For instance, have they complained to you about anything, or been less friendly than usual?

(a) frequently

(b) occasionally

(c) never

Appendix G

PANAS Scale

This scale consists of a number of words that describe different feelings and emotions. Read each item and then mark the appropriate answer in the space next to that word. Indicate to what extent you have felt this way during the past few weeks when you think of

____________________.

1	2	3	4	5
very slightly	a little	moderately	quite a bit	extremely

_____ interested

_____ distressed

_____ excited

_____ upset

_____ strong

_____ guilty

_____ scared

_____ hostile

_____ enthusiastic

_____ proud

_____ irritable

_____ alert

_____ ashamed

_____ inspired

_____ nervous

_____ determined

_____ attentive

_____ jittery

_____ active

_____ afraid

Appendix H

Handout for Feedback Session with Participants

Needs, Support, and Burden: The Experiences of Families and Individuals with Mental Illness

Feedback session on the results of the study - February 15, 1989

This package contains some of the results of the study. The needs, the degree that each need was met, and the suggestions made by participants are reported in this package. Because of the large number of suggestions made for each need, summary statements of these suggestions were prepared. This package also contains the results of the burden and stress (emotional) scales.

Results on the demographic data, issues and concerns for each need, correlational analyses between the degree of need, burden, and stress were not included. These results will be available in the final report. This report will be available in March, 1989.

All results will be presented and discussed at the workshop that will be held March 9, 1989 at the Airlane Hotel.

In this package you will find:

1. Needs for Information and Practical Help, p. 146
2. Needs for Financial and Tangible Assistance, p. 160
3. Needs for Social and Emotional Support, p. 175
4. Scores on Burden and Stress Scales, p. 186

Need: information about the nature of the disorder

Degree of need:	%
no need at all	0
a little bit of need	0
quite a bit of need	100
Degree of need met:	
this need is not met	0
this need is met a little bit	56
this need is met quite a bit	44

Summary statements for suggestions:

Professionals who work with individuals with mental illnesses must be educated about the nature of the illness, the effects of the illness on the individual and the family, the effects of medications, and how to make use of a team approach to help individuals and their families.

Individuals with the illness and family members want to be included in the development of the treatment plan and in the selection of appropriate referrals.

Individuals with mental illnesses and their families need immediate referral to self-help groups, support groups and to hospital education programs. All mental health professionals should be aware of the value of these services and they should ensure that their clients are told of them.

Public education about mental illness and the experience of mental illness is essential. The media should be used in a variety of ways to attain this goal.

Suggestions:

- make use of the media to teach the public about mental illness (53%)
- immediate referral to self-help and support groups (50%)
- educate doctors, psychiatrists, mental health workers, and other professionals to increase their understanding of the illness and its effects (41%)
- referral to trained mental health workers (41%)
- the use of a team approach to treatment (38%)
- active response by hospital staff, reflected by referral to education programs (34%)
- increase research, to increase understanding of the causes of the illnesses, to find a cure, to explore factors such as nutrition and heredity, etc. (31%)
- professionals should take a more active role in treatment (i.e., compassionate, honest, etc.) (28%)
- LPH should provide a list of accurate and helpful reading references (28%)
- include the family in the treatment plan (25%)
- education, help, and counselling for family members, siblings, and children (ask families what they need) (22%)
- the treatment approach should reflect a need to address a variety of individuals with different needs (22%)
- changes in the Mental Health Act - confidentiality should not be used by professionals to exclude family members when the individual wants them to be included in the treatment plan (22%)

- families want counselling (22%)

- make use of the individual as a resource for information about the illness (22%)

- educate other agencies that come into contact with families, such as public health nurses, Children's Aid Society, the police, Justices of the Peace, etc. (19%)

- educate hospital staff about the illness (16%)

- community follow-up (13%)

- expand the role of social workers - more one-to-one work with individuals and their families (9%)

- on-going support for the individual in the community (6%)

- 24-hour crisis centre and hotline (6%)

- evaluation of the whole Ontario Hospital system (3%)

- educate patient advocates about the illness (3%)

Need: information about medications, their effects, and side effects

Degree of need:	%
no need at all	0
a little bit of need	6
quite a bit of need	94
Degree of need met:	
this need is not met	44
this need is met a little bit	47
this need is met quite a bit	9

Summary statements for suggestions:

When prescriptions for medications are made or changed, the person (doctor or psychiatrist) who prescribes the medication should inform the individual and interested family members about: why the medication was prescribed, the dosage, the side effects, long-term effects, effects on behaviour, effect when alcohol is consumed, the degree of impairment due to the medication, and the effects of the medication on the individual's ability, aptitude, and mood.

As with other illnesses, individuals who take medication must receive follow-up while they are taking this medication to determine if medications are effective, dosage is accurate, side effects are adverse, and medication or dosage should be changed.

Suggestions:

- the person who prescribes the medication should provide a variety of information about the medication, the effects, and side effects (72%)
- family members want to understand medications, the effects and side effects so that they can adjust their expectations (28%)

- pharmacies should have information pamphlets available (28%)

- doctors and psychiatrists should explain to the individual why they are on medication, how the medication works, and why they should stay on the medication (25%)

- medications must be monitored (25%)

- if the family is responsible for monitoring medications, they should be included in the treatment plan, and their input should be valued (22%)

- one-to-one work with a social worker (19%)

- doctors and psychiatrists should answer questions about medications (19%)

- need for follow-up, medications alone are not enough (16%)

- public service program, e.g., public health nurses to monitor and administer medications (should not necessarily be a family responsibility) (16%)

- educate family members about medication, effects, and side effects (13%)

- revise the Mental Health Act so that families who are responsible for monitoring medications can get information about medications, the effects, and side effects (13%)

- improve outpatient services (13%)

- referral to hospital education sessions (13%)

- increase research to find a cure (9%)

- increase research to increase understanding of the effects of medications (9%)

- community support groups should have education sessions on medications, effects, and side effects (9%)

- educate nurses and physicians about medications (9%)
- LPH should provide a package of literature on medications, effects, and side effects (6%)
- use of a team approach for treatment to assess the effects of medications (6%)
- advise families of changes in medication (6%)
- decrease dosages of medication (3%)
- 24-hour crisis centre and hotline (3%)
- public education (3%)

Need: information about how to handle symptomatic behaviour

Degree of need:	%
no need at all	0
a little bit of need	12
quite a bit of need	88
Degree of need met:	
this need is not met	50
this need is met a little bit	31
this need is met quite a bit	19

Summary statements for suggestions:

Doctors, psychiatrists, mental health professionals, and family members need to learn how to deal with behaviours that are attributed to mental illness and medications.

The municipal and provincial police, nurses, emergency room hospital staff, and general practitioners also need to be taught how to recognize symptomatic behaviour and how to help the individual.

Some methods that were recommended to teach people how to handle symptomatic behaviour include: making use of individuals with the illness to teach others about what is best for them at times of crisis, counselling for family members with modelling and role-playing, and making use of support groups where families can share their experiences and learn from each other.

Suggestions:

- immediate referral to self-help and support groups (34%)
- counselling for family members (role-playing, modelling) (28%)
- education programs for family members (28%)

- changes in the Mental Health Act to facilitate admission in times of crisis (25%)

- make use of individuals with the illness to educate professionals and family members about how to handle symptomatic behaviour (25%)

the illness (22%)

- educate professionals about behaviour and how to help the individual at times of crisis (19%)

- 24-hour crisis centre and hotline (19%)

- doctors and psychiatrists should provide some information about behaviour when the diagnosis is made (16%)

- LPH should provide an information package (9%)

- need liaison with community while individual is hospitalized (re: rent, bills, etc.) (9%)

- educate general practitioners (9%)

- facilitate emergency room accessibility in times of crisis (3%)

- comprehensive assessment period during hospitalization (3%)

- community follow-up (3%)

Need: information about limitations due to the illness

Degree of need:	%
no need at all	0
a little bit of need	9
quite a bit of need	91
Degree of need met:	
this need is not met	53
this need is met a little bit	37
this need is met quite a bit	10

Summary statements for suggestions:

Individuals with mental illnesses and family members want education programs that offer practical alternatives and suggestions about what the limitations of the illness are, and how to help the individual cope with these limitations.

Individuals with mental illnesses need community-based rehabilitation programs that take into account the level of the illness and the individual's personality, abilities and aptitudes. This program should focus on individual need, and take into account personality differences, and promote ability and individuality.

Suggestions:

- education programs for family members and individuals with the illness; these programs should provide practical alternatives, suggestions and literature (44%)
- mental health workers should be available to the individuals and family members (28%)
- immediate referral to self-help or support group (25%)

- vocational rehabilitation in the community (25%)

- use of a team approach to deal with these issues (19%)

- counselling for the individual and family members (15%)

- community follow-up and support for the individual and the family (16%)

- educate doctors, psychiatrists, and mental health professionals about limitations due to the illness (13%)

- include family members in the treatment plan (13%)

- educate individuals about the illness (11%)

- educate the general public (6%)

- 24-hour crisis centre and hotline (16%)

- recognition that there are different levels of the illness (6%)

Need: information about level of motivation due to the illness

Degree of Need:	%
no need at all	3
a little bit of need	9
quite a bit of need	88
Degree of need met:	
this need is not met	50
this need is met a little bit	47
this need is met quite a bit	3

Summary statements for suggestions:

Individuals with mental illnesses and family members want referrals to trained mental health professionals who can help them understand and cope with the effects of the illness and medications on the individual's level of motivation.

Suggestions:

- educate families about the effects of illness on motivation - of medications on motivation (63%)
- referral to self-help and support groups (28%)
- educate doctors, psychiatrists, and mental health professionals about the effects of the illness and medications on level of motivation (28%)
- follow-up in the community (22%)
- access to professionals for individuals and family members (22%)
- include issues such as level of motivation in the treatment plan (22%)
- teach problem-solving skills to family members (19)

- need for mental health workers to address these issues with individuals and their families (16%)
- 24-hour crisis centre and hotline (9%)
- provide support for the individual from people other than family members (9%)
- creation of services and programs where individuals can form peer relationships with individuals who do not have a mental illness (9%)
- research to determine the effects of the illness on the level of motivation (6%)
- update and improve occupational therapy and vocational rehabilitation programs (6%)

Need: information on community resources available for individuals with mental illnesses

Degree of need:	%
no need at all	0
a little bit of need	15
quite a bit of need	85
Degree of need met:	
this need is not met	50
this need is met a little bit	44
this need is met quite a bit	6

Summary statements for suggestions:

A directory must be created. This directory should include: a list of all agencies, a description of the role of each agency, the method of referral to the agency, the name of a contact person for each agency, and the location and telephone number of each agency. This directory should be updated once a year.

Trained mental health professionals should be available to work with individuals and their families on an on-going basis. The emphasis should be on meeting the needs of the individual. Mental health workers should: act as a resource for information, provide assistance to the treatment team, act as an advocate for the individual, and provide counselling support for the individual and for family members.

24-hour assistance is needed for individuals and their families during times of crisis.

Suggestions:

- creation of a directory (69%)
- community follow-up programs with mental health workers (56%)
- community programs should be designed to meet the needs of individuals who make use of them (34%)
- make use of families as a resource, include them in the treatment team (34%)
- self-help, support groups and LPH could sponsor speakers from each agency to come and describe the agency (31%)
- creation of a support group for children (22%)
- creation of a support group for individuals with the illness (22%)
- educate doctors, psychiatrists, and mental health workers about available services so that they can make appropriate referrals (22%)
- educate the public about the value of community-based programs (19%)
- educate the police, ambulance attendants, firemen, court officials, etc. about the illness (13%)
- provide information to the individual about what services are available (13%)
- 24-hour crisis centre and hotline (3%)
- services should reflect recognition that contact with individuals who do not have a mental illness is also important (3%)

Need: housing

Degree of need:	%
no need at all	3
a little bit of need	6
quite a bit of need	91
Degree of need met:	
this need is not met	63
this need is met a little bit	34
this need is met quite a bit	3

Summary statements for suggestions:

There is a need for housing which would be designed to meet the needs of individuals with mental illnesses. Geared-to-income housing must be increased and diversified. Many individuals are able to live in the community with some support from mental health professionals and appropriate housing.

Suggestions:

- geared-to-income housing (50%)
- increase the amount of housing available for individuals with mental illnesses (47%)
- community follow-up (38%)
- different types of housing should be available because individuals need different levels of care (38%)
- need supervised group homes (34%)
- a mental health professional should be available 24 hours a day (31%)
- medications could be monitored by group-home staff (28%)

- "rules" for group homes reflect reasonable expectations (25%)

- LPH should provide an information package with a list of the types of housing available (22%)

- individuals need on-going support while living independently (22%)

- housing should not isolate individuals from the community (19%)

- mental health professionals should attempt to determine if families are able to provide housing; ability to provide housing should be based on financial resources, location of residence, and ability to cope

- increase access to hospitals in times of crisis (9%)

- changes are needed in the housing policy; individuals should not lose their home when they are admitted to hospital (9%)

- educate professionals about day-to-day needs of individuals (6%)

- individual's need for privacy must be considered (6%)

- sharing an apartment may be a solution (6%)

Need: education

Degree of need:	%
no need at all	6
a little bit of need	6
quite a bit of need	88
Degree of need met:	
this need is not met	63
this need is met a little bit	28
this need is met quite a bit	9

Summary statements for suggestions:

Education programs should be based on individual aptitude, ability and need.

Vocational/rehabilitation programs should be community-based and should address goals outlined by the individual and his or her mental health worker.

Education programs should be conducted by trained teachers or mental health professionals who recognize the effects of the illness and medications, and stress experienced by individuals.

Suggestions:

- need for the creation of programs which reflect an understanding of the effects of the illness on the individual (63%)
- one-to-one rehabilitation/education (47%)
- educate teachers in such programs about the illness (38)
- adapt existing education programs in colleges and universities (31%)
- assessment of individual aptitude and ability (25%)

- programs should be non-stressful (19%)

- counsellors at government employment/education agencies should be educated about the illness (16%)

- fees for education should be geared to income (13%)

- education programs should not only focus on life skills training (6%)

Need: employment

Degree of need:	%
no need at all	0
a little bit of need	6
quite a bit of need	94
Degree of need met:	
this need is not met	66
this need is met a little bit	32
this need is met quite a bit	2

Summary statements for suggestions:

Supportive employment programs must be created. These programs should involve: education of employers, training of the individual, support for the individual, and a consideration of the aptitudes and abilities of the individual.

Suggestions:

- mental health professionals must understand that feelings of productivity are important to individuals (34%)
- employment programs should not be based on marginal types of employment (34%)
- employment programs should focus on a variety of types of employment (34%)
- employment programs should allow the individual to make use of his/her abilities (25%)
- educate employers about the illness (16%)
- provide support for the individual via mental health workers (16%)

- if individuals cannot work, they should not be forced to do so (16%)

- hospital employment should pay individuals for work of equal value as union employees (13%)

- programs should not focus only on life skills training (13%)

- disability pensions should be based on a "sliding" scale so that individuals can supplement their marginal incomes (13%)

Need: financial assistance

Degree of need:	%
no need at all	0
a little bit of need	0
quite a bit of need	100
Degree of need met:	
this need is not met	38
this need is met a little bit	56
this need is met quite a bit	6

Summary statements for suggestions:

The application for the diability pension should be facilitated by mental health professionals who assist individuals by: providing information about the pension, assisting the individual to apply for the pension, and assisting the individual to obtain medical certificates.

The amount of money of the disability pension must be increased so that individuals can afford: food, clothing, and housing. Presently the amount of the disability pension does not cover the costs of basic needs of a person, nor does it allow the individual to have some spending money for recreation and/or savings. The amount of the pension must be scaled with the cost of living. Individuals with mental illnesses should not have to live at a marginal level because they have a mental illness.

Suggestions:

- increase the amount of the disability pension (72%)
- mental health professionals should be available to help the individual with budgeting (34%)

- the disability pension should be based on a "sliding" scale so that when individuals are able to work, they can supplement their pensions without losing the pension (34%)

- eligibility requirements for the diability pension must be changed as these requirements may preclude many individuals from receiving the pension, i.e., the age of onset precludes many from working for a five-year period before they need the pension (34%)

- information about the disability pension should be easily accessed via mental health professionals and hospital staff (22%)

- need to decrease time taken to diagnose the illness, as this often precludes individuals from receiving the disability pension for a long period of time (22%)

- the amount of the pension must cover more than the "bare necessities" (19%)

- pensions should be scaled so that individuals can provide for their spouse and/or children (13%)

- travelling expenses to other communities for treatment should be reimbursed in full and should not affect the amount of the pension received during the time period (13%)

- educate mental health professionals about the application procedure, and the eligibility requirements of the disability pension program (9%)

- individuals should be allotted money for rent when they are living with their parents (9%)

- parents who provide housing and board should be given income tax deductions (9%)

- educate the government about individuals' needs and the cost of living in the community (9%)

Need: community follow-up

Degree of need:	%
no need at all	12
a little bit of need	15
quite a bit of need	73

Degree of need met:	
this need is not met	78
this need is met a little bit	19
this need is met quite a bit	13

Summary statements for suggestions:

Individuals need community follow-up so that they can live independently. Follow-up programs should be flexible so that as the individual's needs change, more or less support would be provided.

Programs such as Meals on Wheels and Homecare were recommended.

Suggestions:

- one-to-one social workers or mental health workers should be available and be mobile in the community (44%)
- make use of Meals on Wheels (41%)
- make use of Homecare (34%)
- volunteers could provide support in the home (22%)
- provide assistance to family members with follow-up programs (9%)
- community follow-up should be part of the housing program (6%)
- have meals available at one location where individuals can have access to nutritious meals (6%)
- vocational/rehabilitation programs could focus on household skills such as cooking, nutrition, etc. (6%)

- volunteers should not be used for community follow-up (6%)
- CMHA could provide a community follow-up program (6%)
- programs should help decrease the individual's isolation (6%)
- nutrition must be monitored (6%)
- make use of public health nurses in community follow-up programs (3%)
- doctors and psychiatrists should prescribe and/or recommend Meals on Wheels or Homecare (3%)
- this program should be on-going, not intermittent (3)
- make use of peers without mental illnesses in this program (3%)
- make use of other individuals with mental illnesses to provide support when they are able (3%)

Need: help with money management

Degree of need:	%
no need at all	13
a little bit of need	9
quite a bit of need	78
Degree of need met:	
this need is not met	69
this need is met a little bit	25
this need is met quite a bit	6

Summary statements for suggestions:

Trained mental health workers should be available to help individuals with money management. It should be recognized that it is difficult to budget for expenses when the amount of the pension is inadequate.

Doctors, psychiatrists, and mental health professionals need to recognize that spending habits may be a manifestation of the illness.

Suggestions:

- individuals should be referred to trained social workers or mental health workers who can help them manage their money (50%)
- create some education programs on money management for individuals (25%)
- increase the amount of the disability pension - "you can't manage what you don't have" (22%)
- referral to the Lutheran centre (9%)
- protect individuals from people who abuse them by taking their money (9%)

- set up a trust that would be administered by a social worker or mental health worker (6%)

- have case managers to work with individuals (6%)

- change "certification of incompetence" so that physicians do not have to declare that the person is incompetent in order to receive help with money management (6%)

- creation of a program to remove parental responsibility for money management (6%)

- address money management in vocational/rehabilitation programs (6%)

- CMHA could provide a program (3%)

- educate professionals about this issue (3%)

- direct payment of bills by social workers (3%)

- make use of banks to dispense money (3%)

Need: respite services or care

Degree of need:	%
no need at all	0
a little bit of need	42
quite a bit of need	48
Degree of need met:	
this need is not met	88
this need is met a little bit	10
this need is met quite a bit	2

Summary statements for suggestions:

Individuals with mental illnesses, adult family members, and children do need respite services. Suggestions to meet this need have included retreats and follow-up during family absences.

Many family members felt that the hospital should be used to provide respite care. It was noted that none of the individuals with the illness felt that this was a viable alternative.

Suggestions:

- make use of the hospital for temporary respite care (31%)
- have retreats for children (28%)
- have retreats for family members (22%)
- make use of family networks (other members) for respite (19%)
- create a volunteer program, respite care could be managed by peers without mental illnesses (26%)
- creation of a respite care program may be inappropriate (13%)
- creation of a hostel for individuals (6%)
- make use of existing programs from other agencies, e.g., time out

for mom (C.A.S.) (16%).

- make use of support group, see the meeting as an evening away (6%)

- educate the Children's Aid Society about need for respite services for children (3%)

- make use of religious retreats (3%)

- make use of trained volunteers to help the individual while the family is away (3%)

- retreats for individuals with mental illnesses (3%)

- creation of a program like WESTWAY (3%)

Need: continued support

Degree of need:	%
no need at all	0
a little bit of need	6
quite a bit of need	94

Degree of need met:	
this need is not met	22
this need is met a little bit	50
this need is met quite a bit	23

Summary statements for suggestions:

Individuals with mental illnesses and their families need emotional support. Immediate referral to self-help and support groups would address this need in part. Trained doctors, psychiatrists, and mental health professionals who understand this need would be helpful as these persons could then provide emotional support.

Individuals with mental illnesses and their families have recommended that public education might address their need for emotional support. Education would decrease the stigma of mental illness and open a variety of channels for communication and support.

Suggestions:

- immediate referral to self-help and support groups (50%)
- referrals to trained mental health professionals for counselling (38%)
- make use of self-help and support groups to learn coping mechanisms (28%)
- public education (28%)

- make use of existing social networks (22%)
- family education would increase support from within the family (19%)
- educate doctors, psychiatrists, and mental health professionals about the illness and how to help family members (16%)
- make use of individuals with the illness as a resource (13%)
- immediate referral to LPH education/support group (9%)
- families should develop their own coping mechanisms (6%)
- make use of your spouse for support (3%)
- change the Mental Health Act, confidentiality issues often prevent families from receiving information (3%)
- creation of a support group for individuals with the illness (3%)

Need: acknowledgement of family contribution

Degree of need:	%
no need at all	0
a little bit of need	6
quite a bit of need	94

Degree of need met:	
this need is not met	50
this need is met a little bit	28
this need is met quite a bit	22

Summary statements for suggestions:

The contribution that family members make in terms of financial, tangible, social and emotional support must be recognized by doctors, psychiatrists and mental health professionals. Family members must be recognized as credible sources and must be included in the treatment plan.

Individuals with mental illnesses also want to have input in the treatment plan. Treatment plans should focus on the individual's needs.

Suggstions:

- doctors, psychiatrists, and mental health professionals should make use of the family as a credible source (56%)
- include family members in the treatment plan (56%)
- educate doctors, psychiatrists, and mental health professionals about the vital role played by family members (56%)
- referral to trained mental health professionals who could provide emotional support to individuals and family members (34%)
- immediate referral to self-help and support groups (31%)

- create a one-to-one community program with mental health workers who could provide support to individuals and their families (25%)

- mental health professionals should provide feedback to family members (13%)

- make use of existing social support networks (6%)

- educate the public about the role played by family members, this would increase people's understanding of the illness (6%)

- 24-hour crisis centre and hotline (6%)

Need: relief from guilt or worry

Degree of need:	%
no need at all	0
a little bit of need	0
quite a bit of need	100
Degree of need met:	
this need is not met	35
this need is met a little bit	44
this need is met quite a bit	21

Summary statements for suggestions:

Doctors, psychiatrists, and mental health professionals must be educated about the nature of the illness so that family members are not blamed for the illness.

Family members want to receive a wide variety of education so that they can address the needs of individuals in appropriate ways. Knowing how to help individuals will help decrease their feelings of guilt and worry.

Suggestions:

- talk to someone about your guilt and worry (41%)
- referrals to trained mental health workers (41%)
- referral to self-help and support groups (38%)
- public education about these issues (25%)
- families should never be blamed for the illness (22%)
- educate doctors, psychiatrists, and mental health professionals about these needs (22%)
- make use of existing social networks (16%)

- treatment plans should allow the person to take responsibility for their own behaviour (13%)

- 24-hour crisis centre and hotline (13%)

- family members should help each other (6%)

- accurate literature on the nature of the illness (6%)

- talk to your spouse (6%)

- include input from the individual and family members in the treatment plan (3%)

- emotional support should be addressed as soon as possible (3%)

- educate staff in general hospitals (3%)

- change the Mental Health Act as it often precludes family members from receiving the help they need as they are excluded from the treatment plan (3%)

Need: address concerns about the future

Degree of need:	%
no need at all	3
a little bit of need	3
quite a bit of need	94
Degree of need met:	
this need is not met	44
this need is met a little bit	31
this need is met quite a bit	25

Summary statements for suggestions:

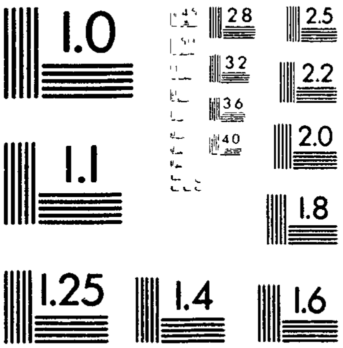
Individuals with mental illnesses and their families recognize that the manifestation of the illness changes over time. They worry about what will happen to the individual in the future. They recommend that we address issues such as on-going support in the community, housing and financial assistance so that the care of the individual will be assured in the future.

Family members need to have access to a trained lawyer who would help them prepare their wills so that they can make provisions for the individual.

Suggestions:

- free legal advice about how to prepare a will to make provisions for the individual in the future (50%)
- immediate referral to self-help and support groups (47%)
- improve all services (47%)
- have mental health workers who can work closely with individuals (34%)

3 OF/DE 3



- alternative and safe housing (16%)
- genetic counselling (9%)
- involve young people as advocates (3%)
- counselling for family members (3%)
- create programs where individuals with the illness are linked with individuals who do not have a mental illness; these programs should be on-going (3%)

Need: for expressed interest and concern

Degree of need:	%
no need at all	0
a little bit of need	9
quite a bit of need	91
Degree of need met:	
this need is not met	28
this need is met a little bit	47
this need is met quite a bit	25

Summary statements for suggestions:

Individuals with mental illnesses need social and emotional support. At this time, they are receiving little or no support aside from the support received by family members. Trained mental health professionals who would understand their concerns would be helpful. An educated public would improve the situation as individuals might then be treated with respect, compassion, and understanding.

Suggestions:

- public education (63%)
- immediate referral to self-nelp and support groups (59%)
- educate professionals to increase their sensitivity and compassion toward individuals (25%)
- need for social events and activities for all family members (22%)
- creation of a self-help group for youths (22%)
- referrals to trained mental health professionals (19%)
- make use of existing social networks (6%)

Need: for on-going emotional support

Degree of need:	%
no need at all	0
a little bit of need	6
quite a bit of need	94
Degree of need met:	
this need is not met	28
this need is met a little bit	41
this need is met quite a bit	31

Summary statements for suggestions:

Individuals with mental illnesses and family members need trained mental health professionals who understand the illness and the effects of the illness on people's lives. They need someone they can call on for advice, counselling, and support.

The value of self-help and support groups must be recognized by doctors, psychiatrists, and mental health professionals. Each client that they work with should be referred to the self-help and support groups.

Suggestions:

- immediate referral to self-help and support groups (75%)
- referral to trained mental health professionals (59%)
- public education (50%)
- educate doctors, psychiatrists, mental health professionals about individuals' and family members' emotional needs (44%)
- 24-hour crisis centre and hotline (22%)
- tailor services to meet need (6%)

- make use of existing social networks (6%)
- make use of family friends (6%)

Frequency of response for items on the burden scale

Item	Frequency Frequently %	 Occasionally %	 Never %
1. missed work due to the person	16	56	28
2. missed school due to the person	9	31	60
3. disruption of social and leisure activities	85	12	3
4. disruption of domestic routine	78	19	3
5. difficulties with the neighbors	28	31	41

Frequency of response for stress scale (emotion)

		Very slightly %	A little %	Moderately %	Quite a bit %	Extremely %
1.	interested	9	6	19	34	32
2.	excited	38	22	16	19	5
3.	strong	50	5	16	3	26
4.	enthusiastic	31	9	19	19	22
5.	proud	6	28	25	22	19
6.	alert	0	3	9	16	72
7.	inspired	25	25	16	19	15
8.	determined	0	13	31	41	15
9.	attentive	38	19	16	16	11
10.	active	31	16	13	25	15
11.	distressed	19	16	16	19	30
12.	upset	25	6	16	25	28
13.	guilty	38	13	16	25	8
14.	scared	50	13	19	6	12
15.	hostile	47	13	19	6	15
16.	irritable	13	13	13	28	33
17.	ashamed	53	16	13	16	2
18.	nervous	9	16	19	22	34
19.	jittery	22	13	22	28	15
20.	afraid	38	16	16	22	8

N.B. order of items presented differs from order given during the interview

Appendix I

Media Campaign

October, 1988	To Your Health	Television
November, 1988	Conversations	Television
February, 1989	Rick Smith Show	Television
February, 1989	Around Town	Television
March, 1989	Ventures North	Radio
March, 1989	Press Release	Newspaper
March, 1989	TBTV News	Television
March, 1989	Chronical Journal	Newspaper

Appendix J

Registration Form for the Workshop - Psychiatric Aftercare: A Consumer's Perspective

PSYCHIATRIC AFTERCARE: A CONSUMERS' PERSPECTIVE

A WORKSHOP ON RESEARCH FINDINGS

SPONSOR

ONTARIO FRIENDS OF
SCHIZOPHRENICS
THUNDER BAY CHAPTER

AIRLANE MOTOR HOTEL
THUNDER BAY

THURSDAY MARCH 9 1989

BACKGROUND

In October 1988, a workshop entitled Psychosocial Rehabilitation: Linking Families & Professionals was held in Thunder Bay. This workshop explored ways of improving services for the psychiatrically disabled and gathered ideas about what services were necessary.

This research project sponsored by the Thunder Bay Chapter of Friends of Schizophrenics is the next step. It was funded by the Secretary of State. It has pinpointed areas of need for improving services for the psychiatrically disabled. Very specific recommendations have come out of the research.

This research is based on a consumer perspective. The goals of this type of research are to return to the community to provide feedback on the research and to share the results and recommendations made by the participants. This particular project has uncovered new areas of concern and has generated novel solutions to the problems of the psychiatrically disabled.

GOALS

1. To bring together psychiatrically disabled individuals, family members and health care professionals to discuss common areas of concern.

2. To develop methods of improving services for the psychiatrically disabled in Thunder Bay.

OBJECTIVES

1. To share the results and recommendations of the research with health care professionals.

2. To develop strategies describing how the psychiatrically disabled, their families and health care professionals can improve specific support services.

3. To develop an overall plan of action for improving support services for the psychiatrically disabled.

AGENDA

:15 Registration & Coffee

:00 Opening Remarks

:30 Method of Study

10.30 Coffee

11:00 Results and Implications of Research Findings

12:00 Lunch

1:00 Advice & Practical Help: Needs & Recommendations

1.20 Small Group Discussion

1:50 Financial & Tangible Assistance: Needs & Recommendations

.10 Small Group Discussion

:40 Coffee

10 Social & Emotional Support: Needs & Recommendations

20 Small Group Discussion

00 Summation & Closing Remarks

FACILITATOR

LYSANNE CHENIER-CHRETIEN
H.B.A., C.F.L.S.,
M.A. (Candidate)

Mrs. Chenier-Chretien has been involved in several independent research projects. Her training and experience have focused on counselling, teaching, psychatric assessment, project design, data collection and analysis. She has an Honours Bachelor of Arts degree and a Certificate in Family Life Studies. She is presently completing a Master's degree in Community Psychology at Wilfred Laurier University, Waterloo.

Mrs. Chenier-Chretien is the principal researcher on the research project which is entitled Needs, Support and Burden: The Experience of Families and Individuals with Mental Illness.

SPECIAL THANKS

The Thunder Bay Chapter of the Friends of Schizophrenics gratefully acknowledges funding assistance for this workshop from:

Secretary of State

Canadian Mental Health Association

Lakehead Psychiatric Hospital

Office for Disabled Persons

*****

Coffee Breaks courtesy of.

Mr. John Deman

Mr. Tom Boland

SunLife

*****

Schizophrenia is the cancer of psychiatry. People afflicted with this disease are regularly in extreme difficulties. If they progress to chronicity, they are truly in terrible trouble--socially, economically, vocationally, psychologically, emotionally, cognitively, and you name it

Donald F. Klein,
Schizophrenia Bulletin,
1980

Mail in Registration Form

For Enrollment in the
Research Workshop:
Psychiatric Aftercare:
A Consumers' Perspective

Place:
Airlane Motor Hotel
Thunder Bay, Ontario

Fee:
$30.00
(Subsidies available for people with minimal income.)

Registration Deadline:
March 2, 1989

Name ____________________

Address __________________

____

Telephone w_______ h_______

Please make cheque or money order payable to:

Ontario Friends of
Schizophrenics
240 Robinson Drive
Thunder Bay, Ontario
807-767-5008 or 807-767-1640

Appendix K

Report on the Workshop - Psychiatric Aftercare: A Consumer's Perspective

Approximately eighty persons attended the workshop. The group was composed of persons with a mental illness, family members, and various professionals.

The first part of the workshop involved a presentation of the purpose of the study and methodology used in the study. The second part of the workshop involved small group discussions. Each small group was composed of persons with a mental illness, family members, and professionals. Each group discussed how the recommendations made by the participants in the study could be applied in the community.

A. Problem-solving needs:

1. Information about the nature of the illness.

- credit course for professionals at a college or university
- education
- issues of confidentiality reconsidered in the Mental Health Act
- media and public education
- compile community resources
- newspaper column as a forum for questions

2. Information about medications, their effects and side effect:

- information on treatment, education, awareness
- need for follow-up
- education on side effects
- increase number of psychiatrists
- issue: drugs, treatment or method of social control

3. Information on how to handle symptomatic behaviour:

- not one form of treatment
- educate families
- make use of the mentally ill as resources to teach professionals and family members
- public health unit and community agencies, if educated could pass on information to families
- broaden scope of treatment to include families
- central referral

4. Information about limitations due to the illness:

- levels of manifestation of the illness change
- should not define limitations of the illness
- aptitude and ability should be considered
- accurate assessment, comprehensive
- community-based programs

5. Information about motivation levels due to the illness:

- individual and medication factors should be considered
- education about these factors is needed
- the person's attitude must be considered (e.g., bored)
- need for directed programs
- need to coordinate referrals with needs and goals of the individual (central)
- change Mental Health Act - these factors are not considered
- use of the media to educate the public
- central referral agency for family members
- individual's ability and personality should be considered

- educate employers about these factors

- consider changes in level of need and ability over time

- housing and a "sense of permanence" may contribute to these factors

6. Information about community resources available for people with a mental illness:

- one person should be responsible for the creation of a directory

- Lakehead Social Planning Council Directory should be a separate section

- every household should have access to it

- need for a Community Information and Referral Centre

- 911 service does need to be considered as a resource for referral

- trained mental health professionals

- need to recognize the effects of the illness on the whole family - and their needs must be recognized

- family members need to have access to resources and need referrals to trained mental health professionals

- need for mental health/illness workers - educate professionals, give them practical skills, increase the mobility in the community of those professionals who work with the mentally ill

- need for a mobile training unit composed of consumers, family members and professionals

- treatment should be geared to the needs of individuals and family members

- need for one-to-one work or case management

- need to have immediate help available for the individual and for family members

- need to evaluate and examine current system and procedures

- creation of a drop-in centre - should be centrally located - should have wheelchair access - need for a security and intercom system at night

- need for telephone access at all times

- need for staff on a 24-hour basis

B. <u>Financial and Tangible Assistance Needs</u>:

1. <u>Housing</u>:

- more housing programs such as "Alphacourt"

- need for settings such as the settings in "approved homes"

- need for subsidized apartments in various buildings

- need for a commitment from the government to increase the quality and number of housing facilities

- need to examine the criteria for waiting lists

- need for different types of housing with different levels of support, e.g., "Castlegreen"

- need to consider "shared-space" housing

- need for representation of people with the illness and family members on committees and boards of directors at Lakehead Psychiatric Hospital and the Canadian Mental Health Association

- need to expand upon community support programs

- need for community follow-up by public health nurses and the Victorian Order of Nurses

2. Education:

- need for identification of specific education needs
- need to adapt existing education programs
- educate teachers about the needs
- creation of tutoring programs
- need to educate the general public and increase public awareness
- need for government incentives for employers to hire the mentally ill in the form of subsidies and grants
- need to consider the person's goals and aptitudes
- need to teach coordinators of vocational rehabilitation programs re: strengths and needs
- professionals must be accountable to the person

3. Employment:

- need for the "Club House" model for transitional employment programs
- need to consider ability to return to the work force
- marginal entry level positions may be a starting point
- need a variety of positions
- need a variety of types of training
- need for a variety of references
- need for support
- need to consider actual employment situation in the community
- need for on-going support
- need for subsidies for employers
- need for cooperative business ventures, e.g., coffee houses
- need to consider non-traditional employment opportunities, e.g.,

resourceful options, self-employment

4. Financial assistance:

- concerning the application procedure: (a) family is often responsible for this task; (b) need to decrease the length of time required to obtain the pension; (c) after the initial waiting period, individuals should not have to wait more than two weeks to have their pension reinstated; (d) need for a pamphlet with information about the disability pension; (e) need to update the whole disability pension system; (f) need to define "disability" CPP, long-term, short-term, welfare, etc.; (g) need for "case managers" to determine when the disability pension is needed - the disability pension should not be discontinued if the person moves to the parental home; (h) also need to: provide a clear outline of what is available, help people to obtain what is available, ensure equal access to resources, decrease the worker/client ratio

- concerning the disability pension: (a) there is little or no incentive to work; (b) persons without a family may be missed in the current system; (c) need to increase the number of subsidized apartments; (d) need to provide different levels of support; (e) need to make use of the Lutheran Community Centre; (f) the "$0.94" incentive is actually working change, the person should be paid minimum wage; (g) Employment and Immigration programs should be used as a model, and these models should be expanded; (h) make use of persons who have had positive experiences and advocates; (i) take note of change and act upon change; (j) need to recognize different levels of need, ability and illness; (k) the values of the work ethic, such as "productivity" should be challenged, the value of work should be addressed, and the mentally ill should not be expected to live at a marginal level; (1) need to make use of a variety of group processes such as: self-advocacy, responsibility for housing, funding, self-help, self-government, and innovative employment

5. Community follow-up:

- need for realistic expectations
- need for independent case management programs, no referral needed for access to these programs

6. Help with money management:

- need to increase the amount of the disability pension
- need to make use of the Lutheran Community Centre
- need for training re: skills
- need for emergency services for people when they "run out of money"
- need to increase awareness of "free" services
- need to train professionals about financial needs
- need for bi-weekly payments versus monthly payments

7. Respite services or care:

- need for one-to-one services
- person's feelings must be considered
- make use of programs such as WESTWAY
- subsidized weekly camps are needed
- consumers and family members need respite
- government funding is needed
- should not need referrals to have access to respite services or care

C. <u>Need for social and emotional support</u>:

1. <u>Continued support</u>:

- greater promotion of Mental Health week

- greater involvement of community service clubs, especially during Mental Health Week

- need for panel discussions to balance public information and to share information

- need to increase public awareness

- need to increase access to information

- need to inform consumers of available community resources before discharge

- need for discharge planning

- recognition of need for support is needed

- need for alternatives other than institutionalization

2. <u>Acknowledgement of family contribution</u>:

- need to recognize effects of the illness at times of crisis

- need to recognize problems of awareness of the illness within the family

- need for case management with monthly case conferences

3. <u>Relief from guilt or worry</u>:

- in order to address this issue, need to recognize the needs of hospital staff and workers in the community and family members by: (a) creating an accurate list of local resources; (b) making use of Lakehead Psychiatric Hospital's "Understanding Schizophrenia"; (c) writing letters to various publishers and authors to voice this need; (d) encourage and commend members of self-help and support groups; (e) make use of your knowledge to teach others; (f) do what you can to improve communication with family members

4. <u>An address of concerns about the future</u>:

- need for trained lawyers to learn how to will your money, and provide information to professionals about how to access lawyers

- need to change legislation so that people can be given an inheritance

- need for community responsibility for tangible support and financial support

5. <u>Expressed interest and concern</u>:

- need to acknowledge social-emotional needs

- need to consider if decreasing recidivism is a priority, should the value be placed on satisfaction, happiness and self-worth instead?

- professional training should include practical training, practical intervention, and methods about how problem-solving needs might best be met

- need for a team who would travel across the province to educate the public and staff at restaurants and fast food outlets where the mentally ill often go

6. <u>On-going emotional support</u>:

- need for education about mental illness and mental health

- need for informed and trained mental health/illness workers to teach others about the illness

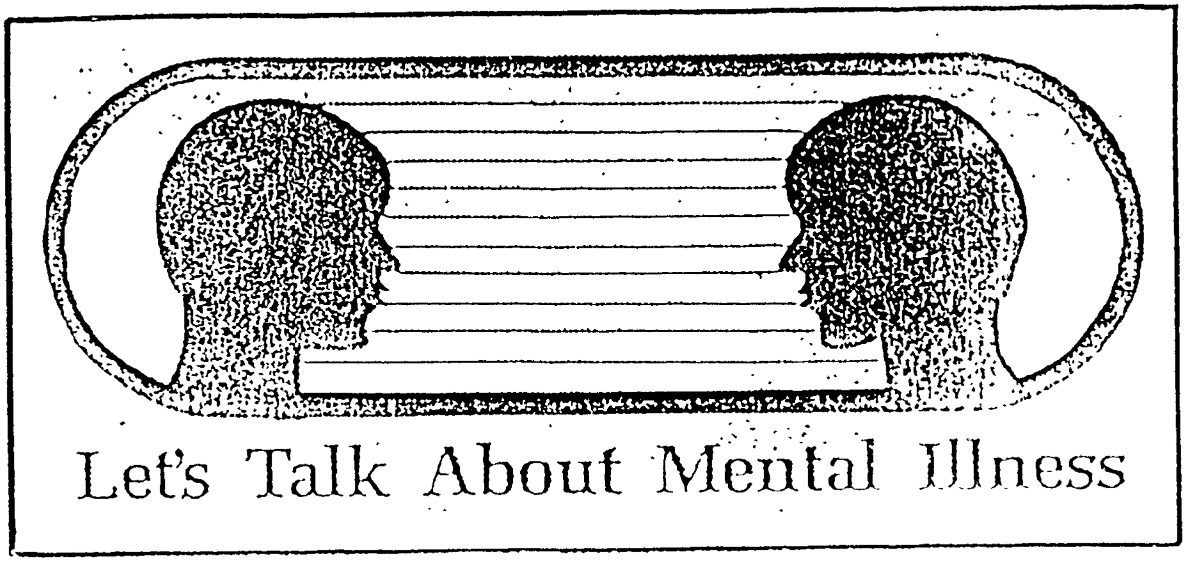
- make use of pharmacists to answer questions about medications and their effects

- recognize the value of self-help and support groups, ensure that professionals are aware of this community resource

This workshop was made possible with funding provided by the Office of Disabled Persons.

Appendix L

Report on the Evaluation of the Workshop - Psychiatric Aftercare: A Consumer's Perspective



Evaluation of the Workshop

Needs, Support, and Burden: The Experience of Families and Individuals
with Mental Illness

by
Lysanne Chénier-Chrétien
March, 1989

Researcher: Lysanne Chénier-Chrétien

Funded by: Office of the Secretary of State,
Thunder Bay Branch
Ontario Friends of Schizophrenics
Thunder Bay Branch

Introduction

The Thunder Bay chapter of Ontario Friends of Schizophrenics held a workshop on Psychiatric Aftercare: A Consumer's Perspective, at the Airlane Motor Hotel on March 9, 1989. The workshop was used in part to report the results of a study which examined the needs of the psychiatrically disabled and the needs of family members living in Thunder Bay, Ontario. This study was funded by the Office of the Secretary of State. The workshop was also used as a means of bringing persons with a mental illness, family members, and mental health professionals together to discuss the needs examined in the study and to generate practical implications of addressing these needs in community-based agencies and provincial facilities in Thunder Bay, Ontario. The Office of Disabled Persons provided funding to defer the costs of this workshop. A report on the discussions and recommendations made at the workshop can be found in the final report of the study. This report is entitled Needs, Support and Burden: The Experience of Families and Individuals with Mental Illness. This report can be obtained by contacting the Thunder Bay chapter of Ontario Friends of Schizophrenics, Bob Schumacher, (807)767-5008.

Those who attended the workshop were asked to evaluate the workshop. The goal of this evaluation was to assist in the planning of future workshops. Approximately eighty persons attended the workshop. Twenty two persons completed the evaluation form.

The evaluation form consisted of six questions. These questions were:

1. How would you rate this workshop?

2. What do you consider the strong points?

3. What do you consider the weak points?

4. What suggestions would you make?

5. What kind of mental health issues would you like to see addressed in future workshops?

6. Other comments

The researcher of the study and facilitator of the workshop reviewed the evaluation forms. The results of the evaluation are reported in general terms.

1. <u>How would you rate this workshop?</u>

The responses included:

- the workshop increased awareness of the need to increase efforts for change in agencies, i.e., to address the needs of persons with a mental illness and the needs of family members (10%)

- the workshop was rated as excellent, very good, good, and fair

- a helpful mechanism to improve the mental health care system

- on a scale of one to ten: 8, 8, 8, 7

- very informative, valuable, effective

- "interesting to find agencies running around being busy and ineffective"

- well-organized

- the results of the study "confirmed some basic needs and concerns"

- well-presented

2. What do you consider the strong points?

The responses included:

- the research and the study
- the summary
- well-informed facilitator
- good presentation of needs (10%)
- identification of practical approaches to improve services for persons with a mental illness and family members (10%)
- opportunity to discuss the development of new services and improvements in existing services
- "mixture of participants - family members, professionals, consumers" (40%)
- discussion period/time
- up-to-date, local, and relevant results of the study (15%)
- well-presented, clear and concise
- facilitator was aware of the issues
- good speaker
- a variety of issues and needs were discussed (7%)
- presentor/facilitator helpful
- good representation from agencies, family members, professionals and persons with a mental illness (5%)
- "realistic goals and values permeated through the entire workshop, also warmth and enthusiasm"

3. <u>What do you consider the weak points?</u>

The responses included:

- "people should volunteer information about what their particular agency can provide in the way of services"
- not enough time for the workshop (45%)
- too much material covered
- repetition of information
- small group discussions were sometimes off topic
- need for use of visual aids
- too little time for small group discussions (50%)
- "examined the gaps, little recognition of the positives in place"
- need to get people involved "beyond a verbal commitment"
- improve organization for registration and seating
- "serious reservations about how much the findings (of the study) will be implemented"
- need to address "misconceptions" promoted by mental health professionals
- shorter period of time for lunch
- difficult to hear facilitator during the afternoon
- too long (10%)
- few solutions provided
- participants not well informed
- professionals "made me feel inferior - listened more than participated"

4. <u>What suggestions would you make?</u>

The responses included:

- begin creating the proposed directory at the workshop

- fewer small groups, i.e., increase the size of the groups

- use of audio visual equipment

- workshop not "empowering"

- use two days for this type of workshop (20%)

- more emphasis on positive changes that have occurred

- personal, hand-written invitations

- send hand-out to participants prior to the workshop and use a brief session to discuss questions on reading material (7%)

- "Persevere!"

- increase community awareness

- "need for organized involvement to ensure implementation"

- "consolidate philosophies in agencies to reduce conflict of implementation"

- could have omitted some information

- use of microphone

- more participation on the part of consumers

- public forums needed

- "apply the values and realistic goals discussed at the workshop"

5. <u>What kind of mental health issues would you like to see addressed in future workshops?</u>

The responses included:

- "how to bring general practitioners, psychiatrists, etc. into the consumer's environment so they can really learn what is necessary"

- focus on what is available

- methods to improve the financial situation of the mentally ill

- formation of committees to promote change
- "medication, treatment, or social control?"
- psychosocial rehabilitation
- hospital care
- legal rights
- future planning
- consumer empowerment
- community resources
- coordination of services
- training of mental health professionals and interdisciplinary teams
- "making relationships - how to teach professionals to help teach clients how to initiate and maintain all kinds of relationships"
- etiology and symptomatology information sessions for new professionals
- information sessions on new developments
- educate professionals about the mandates of other agencies and the referral process
- a session to discuss how consumers feel about the "system"
- have a conference where one member from each agency attends - topics to be discussed: mandate, referral process, access, location, staff, service provided
- public education
- community follow-up
- session to discuss the use of community-based agencies as alternative forms of assistance, e.g., John Howard Society

- "this workshop would be helpful to college and university students who plan to work with the mentally ill"
- educate professionals (20%)

6. Other comments:

The responses included:

- "too bad no doctors felt compelled to attend" (10%)
- good community plan of action
- "I was impressed by your diligence securing Jack Masters' and Joe Commuzzie's attendance"
- few concrete changes will evolve
- need for tables for non-smokers (10%)
- "Congratulations!"
- "Great job!"
- funding is a problem
- good to see F.O.S. sponsoring this workshop
- admirable job

Summary

Those who completed the evaluation form generally felt that the workshop was informative and helpful. The issues were relevant and were focused on local concerns. The attendance of persons with a mental illness, family members and mental health professionals provided a forum for different issues.

Many participants at the workshop found that too little time was allotted to discuss the issues at hand. Future workshops should be longer. An information session for half of one day and a discussion session for a full day might be better. Those who completed the evaluation form felt that the use of small group discussions was useful.

Many suggestions were made for future workshops. Participants proposed that a variety of topics must be presented and discussed. Many of the proposed topics should be addressed in the near future. Participants expressed a need to learn about these issues as soon as possible.

Appendix M

Percentage of Expressed Issues and Concerns, and Suggestions for Problem-Solving Needs

A. Issues and concerns for the need for information about:

1. The nature of the disorder:

- need to understand as much as possible about symptoms and behaviour (34%)
- first-hand experience from others is very helpful (22%)
- psychiatrists and physicians do not know very much about mental illness (22%)
- psychiatrists and physicians don't have time for family members and they don't listen to family members (22%)
- families have to get information on their own, it is a personal responsibility (22%)
- not enough information is provided (22%)
- information is not always accurate (22%)
- family members need a lot of help at the beginning (19%)
- information can only be found in "bits and pieces" (19%)
- families have difficulty accepting the illness, they need help (16%)
- families need information and help to deal with the illness (16%)
- professionals do not understand the illness (13%)
- usually only one family member assumes the responsibility of obtaining information (9%)
- public understanding of the illness is important (9%)
- referral to mental health professionals is crucial (9%)

- diagnosis occurs over a long period of time (6%)
- lack of responsibility by the government increases family responsibility (3%)
- families are not included in the treatment plan (3%)
- there is a long waiting period for family members to see a psychiatrist (3%)
- psychiatrists do not return calls (3%)
- lack of compassion and understanding from some professionals (3%)
- individuals with a mental illness are not protected by the Mental Health Act (3%)
- hospital nursing staff have no time to talk with family members (3%)
- there is little or no follow-up in the community (3%)
- the education program at Lakehead Psychiatric Hospital is helpful (3%)
- individuals with a mental illness should be seen as useful resources (3%)

2. Medications, their effects and side effects:

- families need to understand medications, their effects and side effects so that they can understand behaviour (53%)
- family members are not given any information on medications (44%)
- families have to get this information on their own (38%)
- no information is given (31%)
- families need to be able to recognize side effects (25%)
- families need accurate information and referral to this information from psychiatrists (22%)

- individuals with a mental illness need to be told why they are given medications and the effects of these medications (19%)

- parents must often monitor and administer the medication (19%)

- families need to be involved in the decision making around medications (e.g., changes in medication) (19%)

- there is no information on nutrition and medication (16%)

- need to know about long term effects of medications (16%)

- individuals sometimes will not take their medication (13%)

- families and individuals are not told when medications are changed and why (13%)

- families need time with the psychiatrist so that they can ask questions (9%)

- need to know about limitations due to the medications and the effects of alcohol, and driving abilities (9%)

- professionals don't realize the responsibility that family members undertake (9%)

- medications are not cure, just a control (6%)

- families need to know what could happen if the individual stopped taking his/her medication (6%)

- families need information about suicide and medication (3%)

- individuals must have follow-up to determine the effectiveness of medication (3%)

- medications affect enjoyment of life (3%)

- more medication (larger doses) is prescribed than what is needed (3%)

- people don't know how long it will take for medication to work (3%)

3. How to handle symptomatic behaviour:

- there is a gap in service in the community, need for a crisis centre (28%)
- training programs would be helpful for family members (25%)
- community support groups are not well known in the community, e.g., location, role, service, support, etc. (25%)
- families need to understand symptomatic behaviour (22%)
- the Mental Health Act does not facilitate accessing help when it is needed (hospital admission) (19%)
- individuals with a mental illness are good resources to educate families about symptomatic behaviour (19%)
- a focus on ability versus disability with the individual (16%)
- families are alone (16%)
- symptomatic behaviour can be frightening (16%)
- the police and members of the court do not understand symptomatic behaviour (16%)
- counselling for families should be seen as valuable and needed (16%)
- it is difficult to admit the individual to hospital (13%)
- no suggestions are offered about how to handle symptomatic behaviour (13%)
- handling symptomatic behaviour should be part of an education program (13%)
- people should try to be compassionate and understanding (13%)
- family members often have to deal with behaviour on their own (13%)

- families have to call the police because they have no alternative form of help (13%)
- professionals do not understand symptomatic behaviour (13%)
- families ofter feel responsible and helpless (6%)
- physicians do not understand symptomatic behaviour (6%)
- individuality and personality must be considered when addressing issues such as symptomatic behaviour (3%)
- family is not alerted when individual is hospitalized (3%)
- support group is the only source of information (3%)
- there is no follow-up in the community (3%)
- student counsellors do not understand or recognize mental illness (3%)
- there is little written information on behaviour (3%)
- a team approach would be helpful when addressing issues about behaviour (3%)

4. <u>Limitations due to the illness</u>:

- families don't get this information (31%)
- expectations must be reasonable and must be clarified with the individual (28%)
- need to recognize these limitations (25%)
- there is little focus on ability (22%)
- the individual's goals aren't considered (19%)
- information is not accurate (16%)
- families perform difficult roles (16%)
- professionals don't seem to know about limitations (13%)
- help is essential in times of crisis (9%)

- role of the social worker could be expanded (9%)
- there is no on-going support (9%)
- programs are not tailored to need (6%)
- psychiatrists have too little time for the individual and for family members (6%)
- motivational factors are not considered (6%)
- substance abuse is not considered (3%)
- the individual's attention span is a problem (3%)
- effects of medication may contribute to limitations (3%)
- early signs of the illness are not identified (3%)
- there is too much secrecy about mental illness (3%)
- professionals do not understand what occurs in the home, or the individual's level of functioning (3%)
- physicians are helpful (3%)
- hospital nursing staff do not know how to handle behaviour (3%)

5. <u>Motivation levels due to the illness</u>:

- is motivation part of the illness? (53%)
- families are not told how to deal with this problem (41%)
- having this information helps families have reasonable expectations (41%)
- every individual is different (31%)
- professionals do not talk to the individual about this (16%)
- expectations must be reasonable (13%)
- talking to the individual about these issues is helpful (13%)
- companionship and acceptance for/of the individual contributes to the level of motivation of that individual (9%)

- efforts made to obtain this information from professionals are not welcomed (9%)

- motivation factors may affect compliance to referrals (9%)

- social support should be considered as a means to address motivation factors (6%)

- professionals do not understand motivational factors (6%)

- psychiatrist did encourage family involvement (6%)

- motivational factors may affect appetite (3%)

6. <u>Community resources available for people with a mental illness</u>:

- families need this information (38%)

- programs are not tailored to meet the needs of those making use of them (31%)

- information on community resources is in "bits and pieces" (22%)

- individuals are not given choices (11%)

- there is no information about how to apply for a disability pension (19%)

- there is no list of available resources (19%)

- community support groups are a good resource (19%)

- there is no contact person that is available on a 24-hour basis (16%)

- programs may be harmful and inappropriate (13%)

- programs have "rules" to follow and this is hard for the individual (9%)

- there is no follow-up upon discharge (9%)

- there are no mental health workers who can work on a one-to-one basis (9%)

- demands and expectations on the individual may be too high (9%)

- it is frightening for families to look to community resources (9%)

- referrals are not always appropriate (9%)

- donations for charity could go directly to a person with a mental illness (3%)

- there are different levels of the illness (3%)

- professionals do not know about community-based resources (3%)

B. <u>Suggestions were made to address the need for</u>:

1. <u>The nature of the disorder</u>:

- provide information for family members (53%)

- make use of the media to teach the public about mental illness (53%)

- immediate referral to self-help and support groups (50%)

- educate doctors, psychiatrists, mental health workers, and other professionals to increase their understanding of the illness and its effects (41%)

- referral to trained mental health workers (41%)

- the use of a team approach to treatment (38%)

- active response by hospital staff, reflected by referral to education programs (34%)

- increase research to determine the causes of the illness, to find a cure, to explore factors such as nutrition and heredity, etc. (31%)

- professionals should take a more active role in treatment (i.e., compassion, honesty, etc.) (28%)

- Lakehead Psychiatric Hospital (LPH) should provide a list of accurate and helpful reading references (29%)

- include the family in the treatment (25%)

- education, help, and counselling for family members, siblings, and children (ask families what they need) (22%)

- changes in the use of Form 14 (LPH), all clients/patients should be told of it so that interested family members can be included in the treatment plan (22%)

- families want counselling (22%)

- educate other agencies that come into contact with families such as public health nurses, Children's Aid Society, the police, Justices of the Peace, etc. (19%)

- educate hospital staff about mental illness (16%)

- community follow-up (13%)

- expand the role of social workers - more one-to-one work with the mentally ill and their families (9%)

2. <u>Medications, their effects and side effects</u>:

- the person who prescribes the medication should provide a variety of information about the medication, the effects, and side effects (72%)

- family members want to understand about medications, the effects and side effects so that they can adjust their expectations (28%)

- pharmacies should have information pamphlets available (28%)

- doctors and psychiatrists should explain to the mentally ill person why he/she is on medication, how the medication works, and why he/she should stay on the medication (25%)

- medications must be monitored (25%)

- if the family is responsible for monitoring medications, they should be included in the treatment plan, and their input should be valued (22%)

- one-to-one work with a social worker (19%)

- doctors and psychiatrists should answer questions about medications (19%)

- need for follow-up - medications alone are not enough (16%)

- public service programs, e.g., public health nurses to monitor and administer medications (should not necessarily be a family responsibility) (16%)

- educate family members about medication, effects, and side effects (13%)

- improve outpatient services (13%)

- referral to hospital education sessions (13%)

- increase research to find a cure (9%)

- community support groups should have education sessions on medications, effects, and side effects (9%)

- educate nurses and physicians about medications (9%)

- LPH should provide a package of literature on medications, effects, and side effects (6%)

- use of a team approach for treatment to assess the effects of medications (6%)

- advise families of changes in medication (6%)

- decrease dosages of medication (3%)

- 24-hour crisis centre and hotline (3%)

- public education (3%)

3. <u>How to handle symptomatic behaviour</u>:

- immediate referral to self-help and support groups (34%)
- educational programs for family members (28%)
- changes in the Mental Health Act to facilitate admission in times of crisis (25%)
- make use of the mentally ill to educate professionals and family members about how to handle symptomatic behaviour (25%)
- increase understanding about the individual's experience of the illness (22%)
- educate professionals about behaviour and how to help the mentally ill at times of crisis (19%)
- educate members of the police force (19%)
- 24-hour crisis centre and hotline (19%)
- doctors and psychiatrists should provide some information about behaviour when the diagnosis is made (16%)
- LPH should provide an information package (9%)
- need liaison with community while the mentally ill person is hospitalized (re: rent, bills, etc.) (9%)
- facilitate emergency room accessibility in times of crisis (3%)
- comprehensive assessment period during hospitalization (3%)
- community follow-up (3%)

4. Limitations due to the illness:

- educational programs for family members and the mentally ill; these programs should provide practical alternatives, suggestions, and literature (44%)

- mental health/illness workers should be available to the mentally ill and family members (28%)

- immediate referral to self-help or support groups (25%)

- vocational/rehabilitation in the community (25%)

- use of a team approach to deal with these issues (19%)

- counselling for the mentally ill and family members (16%)

- community follow-up and support for the mentally ill and family members (16%)

- educate doctors, psychiatrists, and mental health professionals about limitations due to the illness (13%)

- educate individuals about the illness (11%)

- educate the general public (6%)

- 24-hour crisis centre and hotline (6%)

5. Motivation levels due to the illness:

- educate families about the effects of the illness and motivation (63%)

- referral to self-help and support groups (28%)

- educate doctors, psychiatrists, and mental health professionals about the effects of the illness and medications on level of motivation (22%)

- follow-up in the community (22%)

- access to professional assistance for the mentally ill and family members (22%)

- include issues such as level of motivation in the treatment plan (22%)

- teach problem-solving skills to family members (19%)

- need for mental health/illness workers to address these issues with the mentally ill and their families (16%)

- 24-hour crisis centre and hotline (9%)

- consider individual differences when considering issues such as level of motivation (9%)

- provide support for the mentally ill from people other than family members (9%)

- creation of services and programs where the mentally ill can form relationships with peers who do not have a mental illness (9%)

- research to determine the effects of the illness on the level of motivation (6%)

- update and improve occupational therapy and vocational/rehabilitation programs (6%)

6. <u>Community resources available for people with a mental illness</u>:

- creation of a directory of services for the mentally ill (69%)

- community follow-up should be designed to meet the needs of individuals who make use of them (34%)

- make use of families as a resource, include them in the treatment plan (34%)

- self-help, support groups and LPH should sponsor speakers from each agency to come and describe the agency (31%)

- creation of a support group for children (22%)
- creation of a support group for the mentally ill (22%)
- educate doctors, psychiatrists, and mental health workers about available services so that they can make appropriate referrals (22%)
- educate the public about the value of community-based programs (19%)
- educate members of the police force, ambulance attendants, firemen, court officials, etc. about the illness (13%)
- provide information to the mentally ill about what services are available (13%)
- 24-hour crisis centre and hotline (3%)
- services should reflect the recognition that contact with persons who do not have a mental illness is also important (3%)

Appendix N

Percentage of Expressed Issues and Concerns, and Suggestions for Financial and Tangible Assistance Needs

A. Issues and concerns for the need for:

1. Housing:

- family members cannot assume responsibility for providing living accommodations for the mentally ill person (31%)
- parents need support if the individual is living in their home (31%)
- if there is no family to provide housing there are few alternatives (31%)
- there are no clear alternatives (31%)
- parents are often responsible for paying rent for the individual (25%)
- individuals should not be in a situation where they isolate themselves (22%)
- the mentally ill need a place of their own (19%)
- individuals should not lose their housing accommodations when they are admitted to hospital (19%)
- inappropriate housing situations may exacerbate symptoms (16%)
- the mentally ill should not be "ghetto-ized" (9%)
- group homes are not satisfactory alternatives (6%)
- housing should not be privatized (6%)
- individuals often make use of welfare benefits (6%)
- there is very little housing available (6%)
- there is no respite care centre (6%)

- individuals often leave the hospital with nowhere to go (6%)
- price of housing is too high (6%)
- living with family members affects family relationships (6%)
- limited housing is available because mental illness is not seen as an illness (6%)
- it is difficult to find out what is available (6%)
- housing programs should be designed to meet the needs of the mentally ill (6%)
- there are long waiting lists for subsidized housing (6%)
- supervision in housing accommodations is necessary (3%)
- individuals need to feel that they have a home (3%)

2. <u>Education</u>:

- when designing education programs, the effects of the illness and medications must be recognized (28%)
- programs should focus on self-worth, self-esteem, and the person's abilities (25%)
- there are no programs available to meet education needs (22%)
- the individual's goals must be considered
- formal post-secondary system does not meet the needs of these individuals (13%)
- program curriculum should acknowledge age of onset of illness (13%)
- aptitude and achievement should be considered (13%)
- there are some programs but they are not suited to need and ability (9%)
- individuals have few choices (9%)

- the mentally ill should not be sent to programs designed for adolescents (6%)

- appropriate referrals are not made (6%)

- need to recognize that the individual may not be able to work or return to work (6%)

- later in life is not the time to begin educating the mentally ill (3%)

- education programs may give the individual something to do with his/her time (3%)

3. Employment:

- feelings of productivity are important (34%)
- menial work is not enough (25%)
- need to acknowledge ability versus disability (25%)
- employers do not understand the illness (16%)
- stress may affect performance (16%)
- there is little or no supportive employment (16%)
- may have to accept that the individual may never work (16%)
- hospital programs are not helpful, do not increase self-worth (13%)
- some programs are degrading (13%)
- minimal wages reflect public attitude of the worth of the mentally ill (13%)
- employment would improve community living and public acceptance (6%)
- there are few choices for employment (6%)
- there is no incentive within the system to work, because of loss

of disability pension once the individual begins working (3%)

4. Financial assistance:

- these individuals are vulnerable, little money may increase stress and exacerbate the illness (50%)
- individuals often do not have enough money for food (34%)
- the mentally ill shouldn't have to live at a marginal level (28%)
- the family's contribution is not recognized (28%)
- individuals should not have to receive welfare benefits because they have an illness (13%)
- the current system makes it difficult to get money (13%)
- the amount of the disability pension does not cover the costs of basic needs for food, rent, and clothing (13%)
- psychiatrists do not facilitate the process that must be followed in order to obtain the disability pension (9%)
- individuals need money to live in the community (9%)
- money helps the individual help him/herself (9%)
- because of the age of the onset of the illness, individuals may not have learned budgeting skills (9%)
- the disability pension is not scaled with the cost of living (6%)
- having little or no money is a discouraging situation for the individual (6%)
- spending habits may be a manifestation of the illness (6%)
- poverty affects self-esteem (6%)
- unions prevent individuals from having earning power (3%)
- increases in the pension could improve the housing situation (3%)
- need to recognize that some individuals can work (3%)

- the individual should not have to sign away all possessions (e.g., real estate) to obtain financial assistance (3%)

5. Community follow-up:

- parents provide much or all of this support (22%)
- it is assumed that it is a parental responsibility (19%)
- no services are available (19%)
- providing this support is a conflicting role for parents (16%)
- these services would give the family some independence (13%)
- individuals may be receptive to outside help (6%)
- it may not be needed by everyone (6%)
- individuals may not be receptive to this service (6%)
- these services are especially important for individuals with no family (6%)
- individuals need some help after they are released from hospital (3%)
- Lutheran community services are helpful (3%)
- parents need support especially if they are older or ill (3%)
- these services are needed daily (3%)
- lack of service reflects lack of government and public concern (3%)

6. Help with money management:

- spending may be a manifestation of the illness (41%)
- because of the age of the onset of the illness, individuals may not learn budgeting skills (22%)
- this is a conflicting role for parents (19%)
- parents often support the individual at their own expense (16%)

- individuals need to be protected from religious organizations who may try to take their money (13%)

- it is hard to manage money when there is little to manage (9%)

- social workers are not helpful (9%)

- individuals might object to assistance (3%)

- dispensation of the disability pension is slow, something is needed in the meantime (3%)

- causes difficulties for mentally ill individuals who are married (3%)

B. <u>Suggestions were made to address the need for</u>:

1. <u>Housing</u>:

- geared-to-income housing is needed (50%)

- increase the amoun+ of housing available for the mentally ill (47%)

- community follow-up (38%)

- different types of housing should be available because the mentally ill need different levels of care (38%)

- need for supervised group homes (34%)

- a mental health professional who understands the illness should be available 24 hours a day (31%)

- medications could be monitored by group home staff (28%)

- "rules" for group homes should reflect reasonable expectations (25%)

- LPH should provide an information package with a list of the types of housing available (22%)

- individuals need on-going support while living independently

(22%)

- housing should not isolate the mentally ill from the community (19%)

- mental health professionals should attempt to determine if families are able to provide housing; ability to provide housing be based on financial resources, location of residence, and ability to cope (13%)

- increase access to hospitals in times of crisis (9%)

- changes are needed in the housing policy; the mentally ill should not lose their home when they are admitted to hospital (9%)

- educate professionals about day-to-day needs of the mentally ill (6%)

- a person's need for privacy must be considered (6%)

- sharing an apartment may be a solution (6%)

2. <u>Education</u>:

- need for the creation of programs which reflect an understanding of the effects of the illness on the person (63%)

- one-to-one rehabilitation/education (47%)

- educate teachers in such programs about the illness (38%)

- adapt existing education programs in colleges and universities (31%)

- assessment of individual aptitude and ability (25%)

- programs should be non-stressful (19%)

- counsellors at government employment/education agencies should be educated about the illness (16%)

- fees for education should be geared to income (16%)

- educational programs should not only focus on life skills training (6%)

3. Employment:

- mental health professionals must understand that feelings of productivity are important to the mentally ill (34%)

- employment programs should not be based on marginal types of employment (34%)

- employment programs should allow the person to make use of his/her abilities (25%)

- educate employers about the illness (16%)

- provide support to the person via mental health/illness workers (16%)

- if the mentally ill person cannot work, he/she should not be forced to do so (16%)

- hospital employment should pay the mentally ill for work of equal value as they do for the union employees (13%)

- programs should not focus only on life skills training (13%)

- disability pensions should be based on a "sliding" scale so that the mentally ill can supplement their marginal incomes when they are able (13%)

4. Financial assistance:

- increase the amount of the disability pension (72%)

- mental health professionals should be available to help the person with budgeting (34%)

- the disability pension should be based on a "sliding" scale so that when individuals are able to work, they can supplement their pensions without losing the pension (34%)

- eligibility requirements for the disability pension must be changed as these requirements may preclude many persons from receiving the pension, i.e., the age of onset of the illness often precludes many from working for a five-year period before they need the pension (34%)

- need to decrease the time taken for diagnosis of the illness, as this often precludes persons from receiving the disability pension for a long period of time (22%)

- information about the disability pension should be easily accessed via mental health professionals and hospital staff (22%)

- the amount of the pension must cover more than the "bare necessities"

- pensions should be scaled so that individuals can provide for their spouse and/or children (13%)

- travelling expenses to other communities for treatment should be reimbursed in full and should not affect the amount of the pension received during that time period (13%)

- educate mental health professionals about the application procedure, and the eligibility requirements of the disability pension program (9%)

- the mentally ill should be allotted money for rent when they are living with their parents (9%)

- parents who provide housing and board should be given income tax deductions (9%)

- educate the government about mentally ill persons' needs and the cost of living in the community (9%)

5. Need for community follow-up:

- one-to-one social workers or mental health/illness workers should be available and be mobile in the community (44%)

- make use of Meals on Wheels (41%)

- make use of Homecare programs (34%)

- volunteers could provide support in the home (22%)

- provide assistance to family members with follow-up programs (9%)

- community follow-up should be part of the housing program (6%)

- have meals available at one location where the mentally ill can have access to nutritious meals (6%)

- vocational/rehabilitation programs could focus on household skills such as cooking, nutrition, etc. (6%)

- volunteers should not be used for community follow-up (6%)

- CMHA should provide a community follow-up program (6%)

- programs should help decrease the person's isolation (6%)

- nutrition must be monitored (6%)

- make use of public health nurses in community follow-up program (3%)

- doctors and psychiatrists should prescribe and/or recommend Meals on Wheels or Homecare (3%)

- this program should be on-going, not intermittent (3%)

- make use of peers without a mental illness in this program (3%)

- make use of the mentally ill to provide support to others with a mental illness (when they are able) (3%)

6. Help with money management:

- the mentally ill should be referred to trained social workers or mental health/illness workers who can help them manage their money (50%)

- create education programs on money management (25%)
- increase the amount of the disability pension - "you can't manage what you don't have" (22%)
- referral to the Lutheran centre (9%)
- protect the mentally ill from people who abuse them by taking their money (9%)
- set up a trust that would be administered by a social worker or mental health/illness worker (6%)
- have case managers to work with the mentally ill (6%)
- change "certification of incompetence" so that physicians do not have to declare that the person is incompetent in order to receive help with money management (6%)
- creation of a program to remove parental responsibility for money management (6%)
- address money management issues in vocational/rehabilitation programs (6%)
- CMHA should provide a program (3%)
- educate professionals about this issue (3%)
- direct payment of bills with the help of a social worker (3%)
- make use of banks to dispense money (3%)

7. <u>Respite services or care</u>:

- make use of the hospital for temporary respite care (31%)
- have retreats for children (28%)
- have retreats for family members (22%)
- make use of family networks (other members) for respite (19%)

- create a volunteer program, respite care could be managed by peers without a mental illness (16%)

- creation of a respite care program may be inappropriate (13%)

- creation of a hostel for the mentally ill (6%)

- make use of existing programs from other agencies, e.g., time out for mom (C.A.S.) (6%)

- make use of support group, see the meeting as an evening away (6%)

- educate the Children's Aid Society about the need for respite services for children (3%)

- make use of religious retreats (3%)

- make use of trained volunteers to help the person while the family is away (3%)

- retreats for the mentally ill (3%)

- creation of a program like WESTWAY (3%)

Appendix O

Percentage of Expressed Issues and Concerns, and Suggestions for Social-Emotional Support Needs

A. These are the issues and concerns about meeting the need for:

1. Continued support:

- family members feel very alone (25%)
- the experience is draining (16%)
- there is no one to turn to (16%)
- spousal support is especially helpful (13%)
- friends could be more helpful and supportive (13%)
- family members need someone to talk to (13%)
- other family members need to learn about the illness and provide more support (13%)
- society has defined mental illness a a family problem (9%)
- people are judgemental (9%)
- the general public is not interested because there is a lack of knowledge and understanding of the illness (9%)
- family members need to be accepting of alternative modes of treatment (vitamine theory) (6%)
- the community support group is helpful (6%)
- people are not understanding (6%)
- professionals are not always supportive (6%)
- family members need to stay "well" to help the individual be "well" (6%)
- the community support group could be more supportive (3%)
- there is nothing on-going after hospital discharge (3%)

- family members need to check their "perceptions" of the individual's behaviour (3%)

- the whole situation can make family members feel angry (3%)

- family members do not want to be told to institutionalize the individual (3%)

- there is a stigma attached to mental illness (3%)

- it is stressful when other parents of mentally ill persons are not supportive of you (3%)

- family members should talk about their concerns with others, they may find that others understand more than the family member originally believed (3%)

- professionals should not assume that family members can accept and/or understand the illness (3%)

- family members may feel trapped because of their feelings of fear (3%)

2. <u>Acknowledgement of family contribution</u>:

- professionals do not listen to family members (31%)

- professionals do not understand (28%)

- family members can provide useful input to treatment (22%)

- present methods of treatment alienate family members from each other, and they often feel excluded (19%)

- family members want some support from professionals (16%)

- the illness has stressful effects on the marriages of parents (9%)

- there is no one to turn to (9%)

- some professionals do realize the valuable contribution made by family members (6%)

- family members' feelings should be acknowledged (3%)

- family members should not have to wait for a crisis before their contribution is acknowledged (3%)

- family members must explore "different avenues" to find support (3%)

- the general public does not recognize the contribution made by family members (3%)

- mental illness is not considered a physical illness (3%)

3. <u>Relief from guilt or worry</u>:

- family members need a "friend", someone they can talk to (34%)

- professionals must stop blaming families for the illness (13%)

- professionals are not available for family members (13%)

- there is no one to turn to (13%)

- it is hard for family members to admit the individual to hospital (9%)

- it is difficult for family members to know what is best for the person (9%)

- people and professionals misunderstand the illness and the person (9%)

- the process of experiencing emotions is important for family members (e.g., denial, anger, grief, mourning, etc.) (9%)

- the treatment team ignores the family, their needs, and concerns (6%)

- it is especially difficult for family members at the beginning, onset of the illness (6%)

- visits with doctors are not long enough, psychiatrists and physicians do not get a clear picture of the individual's level of functioning in the home (6%)

- professionals are fearful of the power of self-help and support groups (3%)

- family members need help or they may become depressed (3%)

4. An address of concerns about the future:

- the mentally ill cannot care for themselves at all times, family members worry about what will happen to the mentally ill person if family members are no longer able to care for them (59%)

- family members need to feel that there is hope for something better for the person (31%)

- the community support group has been attacking these issues in earnest (16%)

- family members should not be responsible for the care of the mentally ill person when parents and/or the spouse are no longer able to do so (13%)

- family members need to talk about this concern (3%)

- at this time, family members cannot leave the mentally ill person money or real estate in a will because this will interfere with the disability pension, and often the individual is not able to manage money (3%)

- this concern is difficult for all family members (3%)

5. <u>Expressed interest and concern</u>:

- family members often feel very alone (38%)

- sensitivity from others is important (38%)

- the stigma associated with mental illness is a barrier (34%)

- people ignore the person and the illness (25%)

- other family members are often insensitive (25%)

- the general public does not understand mental illness (16%)

- there is a lack of public interest in mental illness (16%)

- siblings of the mentally ill person often alienate themselves from the family (13%)

- the general public has poor attitudes about mental illness (13%)

- family members feel encouraged when people show concern (13%)

- talking about concerns is helpful (13%)

- ridicule from people is difficult for family members to deal with (16%)

- people are fearful of what they do not understand (6%)

6. <u>On-going emotional support</u>:

- there is no on-going emotional support (28%)

- self-help and community support groups are helpful (25%)

- psychiatrists are not available for the individual or for family members (16%)

- the community rejects the individual (16%)

- people don't understand the illness (13%)

- professionals and family members must recognize that the needs of a mentally ill person change over time (9%)

- siblings are not understanding (6%)

- family members often feel isolated and alone (16%)

- family members tire of telling professionals the same "story" repeatedly (6%)

- trust is an important issue for family members especially when they are dealing with other family members and professionals (6%)

- special occasions such as Christmas and birthdays are often difficult (3%)

- professionals do not give family members any feedback (3%)

- it is easier for family members to cope with the illness when they have information about the illness (3%)

B. Suggestions were made to address the need for:

1. Continued support:

- immediate referral to self-help and support groups (50%)

- referrals to trained mental health/illness professional for counselling (38%)

- make use of self-help and support groups to learn coping strategies (28%)

- public education (28%)

- make use of existing social networks (22%)

- family education would increase support from within the family (19%)

- educate doctors, psychiatrists, and mental health professionals about the illness and how to help family members (16%)

- make use of the mentally ill as a resource (13%)

- immediate referral to LPH education/support group (9%)

- families should develop their own coping mechanisms (6%)

- make use of your spouse for support (3%)

- change the Mental Health Act, confidentiality issues often prevent families from receiving information that would help to decrease their need for social-emotional support (3%)

- creation of a support group for individuals with the illness (3%)

2. <u>Acknowledgement of family contribution</u>:

- doctors, psychiatrists, and mental health professionals should make use of the family as a credible source (56%)

- include family members in the treatment plan (56%)

- educate doctors, psychiatrists, and mental health professionals about the vital role played by family members (56%)

- referral to trained mental health professionals who could provide emotional support to the mentally ill and family members (34%)

- immediate referral to self-help and support groups (31%)

- create a one-to-one community program with mental health workers who could provide support to the mentally ill and their families (25%)

- mental health professionals should provide feedback to family members (13%)

- make use of existing social support networks (6%)

- educate the public about the role played by family members, this would increase people's understanding of the illness (6%)

3. <u>Relief from guilt or worry</u>:

- talk to someone about your guilt and worry (41%)

- referrals to trained mental health/illness workers (41%)

- referral to self-help and support groups (38%)

- public education about these issues (25%)

- families should never be blamed for the illness (22%)

- educate doctors, psychiatrists, and mental health professionals about these needs (22%)

- make use of existing social networks (16%)

- treatment plans should allow the persons to take responsibility for their own behaviour (13%)

- 24-hour crisis centre and hotline (13%)

- family members should help each other (6%)

- accurate literature on the nature of the illness (6%)

- talk to your spouse (6%)

- educate staff in general hospitals (3%)

- include input from the mentally ill and family members in the treatment plan (3%)

- emotional support should be addressed as soon as possible (3%)

- change the Mental Health Act as if often precludes family members from receiving the help they need, as they are excluded from the treatment plan (3%)

4. <u>An address of concerns about the future</u>:

- free legal advice about how to prepare a will to make provisions for the individual in the future (50%)

- immediate referral to self-help and support groups (47%)

- improve all services (47%)

- have mental health/illness workers who can work closely with the mentally ill (34%)

- alternative and safe housing (16%)

- genetic counselling (9%)

- involve young people as advocates (3%)

- counselling for family members (3%)

- create programs where individuals with the illness are linked with peers who do not have a mental illness; these programs should be on-going (3%)

5. Expressed interest and concern:

- public education (63%)

- immediate referral to self-help and support groups (59%)

- educate professionals to increase their sensitivity and compassion towards the mentally ill (25%)

- need for social events and activities for all family members (22%)

- creation of a self-help group for youths (22%)

- referrals to trained mental health professionals who understand the illness (19%)

- make use of existing social networks (6%)

6. On-going emotional support:

- immediate referral to self-help and support groups (75%)

- referral to trained mental health professionals (59%)

- public education (50%)

- educate doctors, psychiatrists, mental health professionals about individual's and family members' emotional needs (44%)

- 24-hour crisis centre and hotline (22%)

- tailor services to meet need (6%)

- make use of family and friends (6%)

Appendix P

Frequency of Responses to Items on the Burden Scale

	Frequency (n*)			
Items	Never	Occasionally	Frequently	Not applicable
1. missed work due to the person	9	18	5	0
2. missed school due to the person	16	10	3	3
3. disruption of social and leisure activities due to the person	1	3	27	1
4. disruption of household or domestic routine due to the person	1	6	25	0
5. difficulties with the neighbors	13	10	9	0

* where n is the number of participants who responded

Appendix Q

Frequency of Responses to Items on the PANAS Scale

	Frequency (n*)				
Items	Very slightly	A little	Moderately	Quite a bit	Extremely
Positive Affect					
1. interested	3	2	6	11	10
2. excited	12	7	5	6	2
3. strong	5	7	6	5	9
4. enthusiastic	15	4	6	4	3
5. proud	10	3	6	6	7
6. alert	4	4	4	9	11
7. inspired	17	5	4	5	1
8. determined	3	5	6	7	11
9. attentive	0	4	10	13	5
10. active	7	4	7	9	5
Negative Affect					
11. distressed	6	5	5	6	10
12. upset	8	2	5	8	9
13. guilty	16	2	5	2	8
14. scared	12	4	5	8	3
15. hostile	16	4	6	2	4
16. irritable	2	9	8	7	6
17. ashamed	23	5	3	1	10

Frequency (n*)

Items	Very slightly	A little	Moderately	Quite a bit	Extremely
18. nervous	8	8	5	6	5
19. jittery	12	6	5	5	4
20. afraid	10	5	4	8	5

* where n is the number of participants who responded