

SERVICE NEEDS OF FAMILIES

SERVICE NEEDS OF FAMILIES WHERE ONE PARENT HAS AN AFFECTIVE ILLNESS: IMPLICATIONS FOR SERVICE, EDUCATION, AND POLICY

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ABSTRACT

This study explored the service needs of families with a parent with an affective illness. Focus-group and individual interviews were conducted at selected locations across Canada with individuals who had an affective disorder, their partners, and their adult children. A total of 67 participants were recruited.

Corresponding service providers were mailed a questionnaire which asked information regarding these families' needs, the service provider's role with these families, and what prevented or assisted them in addressing those needs. A total of 419 service providers participated in the study.

There was congruence between family-identified needs and the needs identified by service providers. However, there remains a large disparity between the knowledge of needs and having these needs met. The results of this study identify the gaps in service provision and make recommendations for changes in the areas of service, education, and policy-making.

INTRODUCTION

Affective disorders traditionally have been viewed as singular conditions: typically, an individual is diagnosed and treatment is prescribed, but little attention is given to the individual's environment. However, recent research challenges the appropriateness of this individualistic perspective and points to an alternative view in which the family also is considered. There is considerable literature indicating that the effects of an affective disorder are experienced within the individual's social world—

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* Naomi Rae Grant died during the writing of this manuscript. Her wisdom and concern for children and families will continue on.

with her or his family, friends, and work (Coyne, Burchill, & Stiles, 1991; Cummings & Davies, 1994; Hammen, 1992; Wells & Brennan, 1991). It is well established that children growing up in a family with a depressed parent are at increased risk for emotional, social, and academic problems in childhood (Hammen, 1991), and psychopathology in adulthood (Weissman et al., 1987). Further, more marital discord, increased stress, and higher rates of divorce are experienced in families where one parent has an affective disorder than are experienced in families with no ill parent (Teti, Gelfand, & Pompa, 1990).

The major affective disorders are bipolar disorder and major depression. Rates of affective disorders are rising and age of onset is earlier than in previous generations (Klerman 1986; Weissman, Livingston-Bruce, Leaf, Florio, & Holzer 1991). Bipolar disorder—which is characterized by extreme changes in mood, from mania to depression—often occurs at regular intervals throughout adult life in affected people. The prevalence rate for bipolar disorder is 1.2% for both men and women (Weissman et al., 1988). The prevalence rates for major depression are 12.7% for men and 21.3% for women (Kessler et al., 1994). Keller (1992) prospectively followed individuals with depressive illness for a five-year period and found that only 50% of individuals recovered in the first six months, followed by 15% more in the next three months, with up to 5% remaining depressed at five years. Major depression is now viewed as a serious public health problem with significant costs to society. A cross-sectional study of adults seeking treatment for health problems, including depression, found depression rated second only to heart disease in terms of both societal costs and effects on daily functioning and well-being (Wells & Brennan, 1991).

The purposes of this study were: (a) to identify the service needs of families living with a parent suffering from an affective illness; (b) to compare and contrast the needs identified by afflicted parents, partners, adult children, and service providers; and (c) to determine whether identified needs were being met.

LITERATURE REVIEW

In the past two decades, considerable efforts have been spent exploring the effects of parental affective illness on children and on the family as a whole (Beards-lee, Bemporad, Keller, & Klerman, 1983; Coyne & Gotlib, 1983; Downey & Coyne, 1990; Cummings & Davies, 1994; Hodgins et al., 1995). A recent meta-analysis of studies examining the prevalence of mental disorders among children of parents with affective disorders compared to children of non-disordered parents found both that prevalence rates range as high as 61% in the offspring of disordered parents (Hodgins et al., 1995) and that the problems experienced by these children continue into adulthood (Andreason et al., 1987). These high prevalence rates have given rise to a multitude of studies exploring three central hypotheses: (a) genetic inheritance, (b) problems in parent-child relationships, and (c) disruptive family environments. The first hypothesis suggests that there is an inherited predisposition for disorder in children passed from parent to offspring (Klein et al., 1995; McGriffin, Katz, & Rutherford, 1991; Torgensen, 1986; von Korrington, Cloninger, Bohman, & Sigvardsson, 1983; Wender et al., 1986). The second premise suggests that the ill parent's relationship with the child interferes negatively and results in problems within the child (Radke-

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Yarrow, Cummings, Kuczynski, & Chapman, 1985; Teti, Gelfand, Messinger, & Isabella, 1995; Field, Healy, Goldstein, Perry, & Bendell, 1988; Hammen, 1991). The third theory suggests that a mood disorder of the parent negatively affects the environment in which the family lives, thus giving rise to problems in the child as well as in the family as a whole (Hammen, 1991; Teti et al., 1990; Byrne et al., 1997).

Families with a parent who has an affective disorder have been found to have higher rates of marital discord, divorce (Hammen, 1991), stressful life events, unemployment, and poverty (Teti et al., 1990), and to have lower rates of social support (Byrne et al., 1997). Other studies—conducted to explore the meaning of an affective disorder for the individual and the family, and to determine how other adult family members actively attempt to deal with the ill person—have found that the ill individual and the partner separately undergo a process of attempting to understand and deal with the illness (Karp, 1996; Badger, 1996a). These studies also have determined that partners use both protective and coercive strategies when interacting with ill individuals (Badger, 1996a, 1996b).

While there is considerable evidence that children and families experiencing an affective disorder in one parent are at increased risk for problems, there is an absence of consideration in the literature—with the notable exception of one study (Badger, 1996a)—about the needs of these families. In that one study, Badger (1996a) found that families often wanted more information regarding affective illness and its treatment, but were unable to access this information.

METHODOLOGY

This study involved collecting data from parents with an affective disorder (consumers), members of their families (i.e., partners and/or adult children), and service providers. Three different approaches were utilized: (a) focus-group interviews, (b) individual interviews, and (c) a mailed questionnaire. Consumers and family members were interviewed through the use of focus-group or individual interviews; service providers were surveyed using a mailed questionnaire.

Focus-Group and Individual Interviews

Focus groups were conducted in five regions across Canada—the Atlantic region, Quebec, Ontario, Manitoba, and British Columbia. Several of the groups were conducted in large cities and others were offered in rural areas. Local Canadian Mental Health Associations, the Alliance for the Mentally Ill (Quebec), and Depressive and Manic Depressive Associations in the respective sites were contacted, informed about the study, and asked if they were willing to recruit consumers and family members to participate. If agencies were in agreement, times and dates for focus groups were arranged so potential participants could be approached. Provision was made for interviews of individuals who were unable to attend a focus group in their region.

A manual was developed to assist in facilitating both focus-group and individual interviews, and to heighten standardization of questions. The discussions focused on: (a) the issues and concerns of families, (b) how the affective illness impacted on relationships, and (c) services which would be helpful to assist families in coping with the illness. Interviewing was facilitated by one of two authors (CB or YA) to ensure consistency and to build upon the knowledge gained from each prior interview.

Prior to beginning an interview, the purpose of the study was explained, questions were answered, and prospective participants were asked to sign a consent form indicating their willingness to continue with the process and to be audiotaped. They then were asked to complete a profile which provided demographic information, and to participate in audiotaped interviews (which were one to two hours in duration).

A total of 67 individuals participated in this phase of the study (47 consumers, 13 partners, and 7 adult children). Ten focus groups ranging in size from two to eight members were conducted. In addition, 16 individual interviews were conducted with people who were unable to attend focus groups. The consumer group consisted of 22 males and 25 females, of whom 52% reported a diagnosis of bi-polar disorder, 36% reported major depression, 9% reported schizo-affective disorder, and 3% reported dysthymia. The group of partners consisted of four males and nine females. All seven members of the adult-child group were female. As the numbers indicate, more consumers than family members participated in this study. These proportions may reflect the fact that the participating agencies offered more consumer support groups than groups for families. There also were fewer men in the family group than there were women. While the reason for this imbalance is not clear, agency staff did indicate that women family members were more likely than men to attend family support groups.

Audiotapes from the focus-group and individual interviews were transcribed and entered into the NUD-IST program for managing qualitative data. The transcripts first were read and re-read independently by three members of the study team. A study-team meeting was then held in order to identify and agree upon themes and patterns evident in the data. Finally, the transcripts were coded line-by-line according to the themes generated.

Service-Provider Questionnaires

Questionnaires were mailed out to 1833 service providers of individuals with affective disorders in the same five regions where focus groups and interviews were conducted. Family doctors and psychiatrists in each of the selected communities were identified by accessing *Southam's Medical Directory CD ROM* (1996). In the event that the list exceeded 100 physicians per geographic location, random sampling was used by selecting the first, fifth, and tenth physician out of every ten from the Southam Directory. Other health professionals were accessed through the local community information service directories, Canadian Mental Health Associations, and Depressive and Manic Depressive Association staff. Agencies received a phone call prior to the mail-out of the survey, and a brief description of the study was given to an identified person—who usually took on the responsibility of distributing the survey to agency staff.

The survey questionnaire used open-ended questions. Participants were asked to identify: (a) the needs of families, (b) the service provider's role with these families, (c) the factors which either assisted or prevented them from addressing family needs, (d) the community supports which were available, and (e) the gaps between the formal system and community resources.

Of the 1833 questionnaires mailed out to service providers, 419 were returned. This low response rate may be a result of both the lack of follow-up after a single mailing of questionnaires and the use of open-ended questions (which take a longer

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time to complete than would a survey using closed-ended questions). Questionnaires were mailed to 888 family doctors (146 [16%] responded), 647 psychiatrists (178 [27%] responded), and 291 other health professionals (95 [35%] responded).

The answers given by service providers to the open-ended questions also were entered into the NUD-IST program for managing qualitative data. The transcripts were read and re-read by four of the study team members to identify themes and patterns. The transcripts were then coded according to the themes developed.

RESULTS

Consumer and Family Reports About Service Provision

Analysis of the focus-group and individual interviews resulted in the identification of a number of issues, which could be classified within two categories—formal supports and informal supports.

Formal Supports

The formal supports identified in the analysis of focus-group and individual interviews included:

1. *Receiving a Diagnosis.* Participants described difficulties in obtaining a correct diagnosis, which was necessary in order to access the right services and receive the appropriate treatment. There were occasions when the time lag between early signs and symptoms and receiving a diagnosis was years. Sometimes a diagnosis was missed by the physician, and participants received treatment for an assortment of complaints before being diagnosed with an affective disorder:

I knew there was something really wrong. I went to my GP and he would give me sleeping pills. He's very caring, understanding person but we had never put it together. I went to pick up my prescription for sleeping pills and I was sitting in the pharmacy. I read a poster on depression and I said "yes" to every one of the symptoms including all the way to suicide. So, I went to the doctor's office straight from the pharmacy and asked could this be depression? He went through my file of all my previous visits and he said yes and prescribed Paxil and made an appointment with the psychiatrist and I have been under his care since then.

Some participants explained that it was not always a problem of accessing the system but rather an issue of the consumer being reluctant to be diagnosed with a mental illness. Reluctance to accept or seek help and to obtain a diagnosis went hand-in-hand with consumers being worried about the stigma of being labelled mentally ill. One partner commented about his wife's experience:

There is a major hurdle that people have to go through to get help. To make the choice to get drawn into the mental health system. It's hard to make the first step.

2. *Waiting.* Participants not only described lengthy periods of time between the onset of the family member's symptoms, the help-seeking stage, and the diagnosis, but they also identified waiting lists as a barrier. One family member reported a six-month wait to get an appointment for her husband to see a psychiatrist. Others described waiting for long periods of time in emergency rooms. The following letter, written by a family member for the local newspaper after experiencing a wait in an emergency department, was read to the focus group:

I had the unpleasant task of taking a sick relative to our local hospital. We arrived at 10:00 pm and left at 6:30 the following morning when a bed became available in another hospital. My relative was seen by a medical doctor between 10:00 pm and 11:00 pm. I was then told that he would have to be seen by a resident psychiatrist to determine if he needed to be admitted to hospital. We waited until 4:00 am, more than five hours for a psychiatrist to arrive. At 5:00 am I was told that a bed was available at another hospital but the psychiatrist who had seen him could not admit him. It had to be a psychiatrist from the other hospital. At 6:00 am we were told that an ambulance would be called for the transfer but because this type of transfer was low on the priority, we would have to wait four hours. There were no beds in the assessment rooms, only a mattress on the floor. My relative was diagnosed over ten years ago and needed an adjustment of his medication.

3. *Involvement of the Family.* Many participants expressed concern about the lack of family involvement in the treatment process. Family members felt left out of conferences, treatment planning, and discharge planning. They emphasized that the illness impacted not only the consumer but also the family. Many family members described a mood disorder as a family disease, and they felt strongly that families should be involved in the decision-making process concerning the consumer. One wife stated:

One issue I have found, when my husband was in the hospital, is how little the family was involved. He was diagnosed in the hospital and we had no experience with mental illness at all. I kept expecting to get involved in the process. I mean we were all in shock. I had small children at the time. We were in crisis, our family. I kept expecting the hospital to get us involved in his treatment and some training. Nobody ever called me.

A mother who was responding to an institution's lack of family involvement in discharge planning made the point that people in her province who are hospitalized because they are a danger either to themselves or to others can only be kept in hospital for a maximum of 72 hours:

Yes there is certainly a level of frustration. This 72 hours is a farce. They will release the patient in a delusional state assuming the person can fend for themselves and they can't. Who does? The family!

4. *Finding the Right Caregiver.* Participants reported encountering clinicians who recognized a single method of treatment only, with a tendency to use either psychotherapy or medication. One partner described the problems encountered during the family's search for treatment:

We initially started going around to medical doctors because he had very severe headaches. Looking back it was probably anxiety symptoms but we went running around from doctor to doctor and psychiatrists. I feel in the mental health system that one of the worst problems is when you have these turf battles between psychiatrist and psychologist and who should be treating whom and whose territory is it? And the patient is the victim and the family's confused. It's a pet peeve of mine that there is not more co-operation and co-ordination of services.

Another partner described a situation where misdiagnosis led him and his spouse to the wrong type of caregiver, with the result that much wasted time was spent in psychotherapy:

People are rushed through and quite often things are misdiagnosed. Initially a social worker was involved and said we needed some talk therapy. That my wife didn't need medical treatment. Just work through your emotions together. However it wasn't helping!

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5. *Communication with Health Professionals.* Many of the participants identified communication with health professionals as being problematic. Several described phoning for assistance and having an answering machine take their call. Others described health professionals from different programs not talking with one another. There were numerous examples of family members having difficulty communicating with the physician when attempting to be more involved in the care and treatment of the consumer. One family member reported a psychiatrist becoming angry with him for asking questions regarding his spouse's condition. A wife reported that, on her husband's first admission to hospital, the physician was unwilling to talk to her. She decided to stay in the clinic waiting room for many hours to speak to her husband's psychiatrist. Eventually, when the psychiatrist came out, he spoke to her while walking down a corridor—failing even to look at her. Another spouse reported the difficulty she experienced when her husband was admitted to a mental health centre. She was left feeling that, although the basic medical expertise was present, a much better job needed to be done in conveying this competency to her and her family.

While many participants had negative things to report about service delivery and rapport with health professionals, there were also some positive aspects identified. Many spoke of eventually finding the right health-care provider (family doctor, psychiatrist, nurse, or social worker) with whom they were able to establish a good working relationship. Several family members mentioned a local hospital having a direct telephone line which they could contact at any time to get advice. Mood disorder clinics in hospitals were described favourably, especially in the hospitals which provided information and education sessions for consumers and families. Also, hospital volunteers—who could provide support and be available for families when a loved one was admitted—were identified as a special resource and considered very helpful. These volunteer support services were often a collaboration between the institution and the local support group.

Informal Supports

The informal supports identified in the analysis of focus-group and individual interviews included:

1. *Family and Friends.* Many participants identified their informal network of family and/or friends as assisting them in linking up with the right service or agency. For many consumers, knowing someone helped them to gain entry to mental health services "through the back door." This informal network of family and friends also assisted in obtaining other supports outside the health care system, such as child-care, in-home support, and social assistance.

2. *Self-Help Support Groups.* Self-help support groups were viewed by participants as an extremely important vehicle for support and sharing ideas. The majority of participants reflected favourably upon the support and assistance they obtained as a result of being part of a self-help group. There was a definite sense among the participants that support groups provided opportunity for people to understand one another. Hearing people talk about being in similar situations was felt to be, in itself, therapeutic. Many participants believed that professionals could not provide the necessary empathetic responses because they have not lived through the experience.

Several of the participants (consumers and family members) identified the 12-step program which A.A. and Al-Anon organizations advocate for their members as being

very useful not only in dealing with alcoholism, but also in giving them tools to deal with the consequences of depressive and manic depressive symptoms.

Twelve-step program is invaluable for my husband as it is for me. Any solace, support or strategies that I use are twelve step strategies. So for me, that is a very integral part of dealing with this.

Service Providers' Reports of Family Needs and Service Provision

Service providers (i.e., other health professionals, psychiatrists, and family doctors) often responded to the open-ended questions in the questionnaire with one or two word answers. These responses did not allow for the same type of rich descriptions that arose out of the interviews. The themes that evolved from the categories provided on the questionnaire are briefly described below and summarized in tabular format. Four main categories were identified by analysis of the questionnaire responses: (a) the needs of families where one parent has an affective disorder as identified by service providers, (b) the preceptions of service providers about their roles with consumers and their families, (c) the impediments faced by service providers in their attempts to meet the needs of the families, (d) and the supports which service-providers identified as potentially helpful. The issues identified within each of these categories are described briefly below and summarized in tabular format (see Table 1).

Identified Needs of Families

The needs of families, as identified by service providers, clustered around the following issues: (a) education and information, (b) assessment, (c) instrumental support, (d) emotional support, and (e) informal support. All service-provider groups clearly identified the need for families to receive education and information about affective illness and its treatment. Other health professionals and psychiatrists agreed that both children and partners of individuals with an affective illness need to be assessed to determine if they are at risk for an affective illness or other difficulties. All service-provider groups also recognized that families could be experiencing considerable stress and identified the need for in-home support services and respite for families. The respondents universally acknowledged the overwhelming importance of caregivers building supportive relationships with consumers and with their families. Finally, they identified the importance of support groups, such as self-help groups, in providing assistance to families.

Roles of Service Providers

The roles which service providers identified as their perceived responsibilities when working individuals suffering from an affective illness and their families varied across professional groups. Psychiatrists considered their primary role to be in active treatment and education. Family doctors, on the other hand, identified their role as supervising medications. Both physician groups recognized that it was important for them to adopt a supportive role and to assist the consumer and family in accessing other resources. All service-provider groups felt that they had a role in education regarding affective illness. The perceived roles reported by other health professionals included those of counsellor/therapist, case manager, and provider of child protection, shelter, support, and vocational rehabilitation. While all service-provider groups identified needs for the entire family, very few indicated that they had a role with the entire family.

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Impediments to Meeting Families' Needs

Table 2 summarizes the impediments to meeting families' needs which were identified by services providers. All groups of service providers reported having inadequate time to meet family needs. Again, there was considerable agreement across

TABLE 1
Needs of Families with a Parent with an Affective Disorder
(as Identified by Service Providers)

Needs and Issues	Other Health Professionals	Psychiatrists	Family Doctors
Education/ Information	➤ information about illness,* medications	➤ information about illness*	➤ information about illness*
Formal Support:			
Assessment	➤ assessment and management during crisis ➤ assessment for children and partners at risk	➤ assessment for children and partners at risk	
Instrumental Support (tangible aid)	➤ home support services ➤ a co-ordinated approach between home supports (financial aids, etc.)	➤ home-support services (household) ➤ respite for partner and family ➤ financial stress—need for additional financial support due to unemployment ➤ directions to community services	➤ home support services with household tasks
Emotional Support	➤ establishing an ongoing relationship with one person ➤ ongoing support regarding dealing with family relationships ➤ dealing with the affected spouse ➤ dealing with children ➤ anger management ➤ dealing with changing roles ➤ appropriate support for children based on age and stage ➤ self-esteem skills for	➤ establishing a supportive relationship/alliance with the family ➤ ongoing support regarding dealing with family relationships ➤ dealing with the affected spouse ➤ dealing with children ➤ dealing with loss ➤ dealing with guilt ➤ dealing with changing roles ➤ appropriate support for children based on age, stage, and gender	➤ establishing a supportive relationship ➤ ongoing support regarding the dealing with family relationships ➤ dealing with the affected spouse ➤ dealing with children ➤ reductions of guilt ➤ dealing with changing roles ➤ parenting skills

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|---|---|
| family members | ➤ parenting support |
| ➤ support re: communication in the family | ➤ support re: communication within the family |

Informal Support:

- | | | | |
|--------------------------|--------------------------|--------------------|--------------------|
| Informal Supports | ➤ self-help groups | ➤ self-help groups | ➤ self-help groups |
| | ➤ extended family | | |
| | ➤ friends who understand | | |
-

* most frequently identified

the service-provider groups regarding what impeded them in dealing with families with an affectively ill parent. Among the systemic issues identified as impediments to good family care were: (a) fragmented care; (b) lack of contact, knowledge, and coordination between agencies; (c) lack of services (such as homemakers, child care, parenting groups, or self-help groups); (d) lack of subsidized medication costs; and (e) long waiting lists. All service-provider groups pointed out the lack of recognition of families' needs when dealing with an affective disorder. Issues such as treating individual symptomatology, individual rights to confidential treatment, and the majority of funding being placed in adult mental health programs were viewed as barriers to good family care. The stigmatization of mental illness by the general public and within families was another factor identified by all service-provider groups as preventing families from seeking treatment.

Both family doctors and psychiatrists reported that their remuneration schedule interfered with seeing families; a fee-for-service system encourages a rapid turnover of individuals rather than comprehensive care for families. Unlike other health professionals, family doctors and psychiatrists identified a lack of training in their professional education programs to prepare them adequately for dealing with the entire family.

Meeting Family Needs

Service providers identified several things which would assist them in working with families: (a) educational material on affective disorders aimed at parents and children; (b) guidelines on working with the family and assessing children at risk; (c) additional resources (such as parenting mentors, more support groups, and in-home care) being made available; (d) greater collaboration between agencies; and (e) increased public awareness regarding affective disorders (see Table 3).

All groups of service providers referred to the Depressive and Manic Depressive Association support groups, the Canadian Mental Health Association, Mental Health Clinic, Al-Anon, Alcoholics Anonymous, Emotions Anonymous, Mood Disorder Clinics, and Community Redbooks as being helpful community resources for families. However, insufficient numbers of support groups (especially for children and families), the hesitation experienced by some people about attending groups, long waiting lists, and caregivers' own lack of knowledge of community resources were identified as gaps in these resources.

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CONCLUSIONS

Synthesis of the Findings

This study supports the idea that an affective illness impacts on all family members; that is, because of the individual's connectedness to the spouse (as partner) and to the child (as parent), the illness is more than an individual concern.

This study brings together the viewpoints of consumers, families, and service providers regarding the needs of families where one parent has an affective disorder. In so doing, it informs analysis on a number of levels: (a) The information gained through focus-group interviews provides an understanding about service and support needs of such families; (b) the individual interviews provide a rich source of insight into the concerns of families, the effects of illness on the family, and the services which are needed to manage these effects; and (c) the service provider survey indi-

TABLE 2
Service Providers Identification of Impediments to Meeting Families' Needs

	Other Health Professionals	Psychiatrist	Family Doctor
System Issues	<ul style="list-style-type: none"> ➤ lack of community supports ➤ most services offered to adults not youth ➤ medical community works in isolation from other therapists 	<ul style="list-style-type: none"> ➤ lack of community supports ➤ constraints imposed by practice rules (fee-for-service) ➤ tendency to sub-specialize and fragment services ➤ discontinuities between child and adult services 	<ul style="list-style-type: none"> ➤ lack of community supports ➤ family doctors are not included by outside agencies ➤ funding (fee for service)
Service Issues	<ul style="list-style-type: none"> ➤ waiting lists ➤ funding ➤ lack of time ➤ focus on individual client making family assessment difficult ➤ services based on addressing individual symptomatology rather than prevention ➤ services are not sensitive to family 	<ul style="list-style-type: none"> ➤ lack of funding ➤ lack of time 	<ul style="list-style-type: none"> ➤ time ➤ long waiting lists
Treatment Issues	<ul style="list-style-type: none"> ➤ primary client refuses to involve family ➤ family doesn't want involvement due to 	<ul style="list-style-type: none"> ➤ confidentiality issues ➤ family reluctant to be involved due to stigma or frustration 	<ul style="list-style-type: none"> ➤ confidentiality issues ➤ family reluctant due to stigma or frustration

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stigma or frustration
with primary client

Educational Issues	<ul style="list-style-type: none"> ➤ lack of experience ➤ lack of interest ➤ not part of training 	<ul style="list-style-type: none"> ➤ not always aware of community supports ➤ lack of comfort with families ➤ no training in dealing with families
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cates that service providers are very much aware of the issues facing families and that they recognize the barriers to accessing service.

While consumer-, family-, and caregiver-identified issues are not exactly the same, when considered from the domain of their respective viewpoints, they are remarkably similar and balanced. It is clear from the analysis that all groups of service providers are able to identify accurately the needs of family members. There is,

TABLE 3
Service Providers' Identification of What Would Assist in Meeting Family Needs

	Other Health Professionals	Psychiatrists	Family Doctors
Educational Material	<ul style="list-style-type: none"> ➤ better educational material on affective illnesses and their treatment for: <ul style="list-style-type: none"> - parents - teens - children - families ➤ education for general public to reduce stigma 	<ul style="list-style-type: none"> ➤ educational material on affective illnesses and their treatment for: <ul style="list-style-type: none"> - families - parents - children - school system (videos, books, presentations, pamphlets) ➤ continuing medical education 	<ul style="list-style-type: none"> ➤ books/videos on affective illnesses and their treatment for: <ul style="list-style-type: none"> - parents - children - families ➤ education for general public in dealing with family ➤ education for family doctors through: <ul style="list-style-type: none"> - continuing education - residency program
Guidelines	<ul style="list-style-type: none"> ➤ guidelines for assisting: <ul style="list-style-type: none"> - children - family members in coping with illness 	<ul style="list-style-type: none"> ➤ increased information about the needs of families and risk for children 	<ul style="list-style-type: none"> ➤ guidelines for assessing children at risk
Availability of Other Resources	<ul style="list-style-type: none"> ➤ other community resources that will focus on family care ➤ more in-home support for families 	<ul style="list-style-type: none"> ➤ play groups for children ➤ support for new moms ➤ parenting supports ➤ more home-support 	<ul style="list-style-type: none"> ➤ additional community support such as: <ul style="list-style-type: none"> - homemakers - visiting nurses - day program

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	<ul style="list-style-type: none"> ➤ parenting mentors ➤ consultation on how to work with these families ➤ increased number of support groups for families and children 	<ul style="list-style-type: none"> workers ➤ more support groups 	<ul style="list-style-type: none"> - child care - self-help groups for partners and children ➤ easily available, skilled clinicians for consultation ➤ psychiatric backup
Greater Collaboration	<ul style="list-style-type: none"> ➤ collaboration between all service sectors 	<ul style="list-style-type: none"> ➤ greater collaboration between all service sectors ➤ better liaison with school counsellors 	<ul style="list-style-type: none"> ➤ more team work with all professionals to provide long-term family-centred care
Finances		<ul style="list-style-type: none"> ➤ increased financial assistance for meds. ➤ fee schedule allowing for family sessions 	<ul style="list-style-type: none"> ➤ sessional payment vs. fee-for-service

nonetheless, a disjunction between the reality of those needs and the available services. Families identify issues such as accessing the right services, waiting, lack of involvement of the family, finding the right caregiver, and communication with health professionals as problematic areas which contribute to this disjunction. Health professionals, on the other hand, identify as problematic issues such as lack of time, remuneration schedules, lack of preparation in dealing with families, fragmented care, lack of family-oriented services, stigmatization, and the tendency to view affective illness as an individual (as opposed to family) problem.

The analysis of the effects of affective disorders on families has been developed into a handbook (Health Canada, 1999). This handbook, which is intended for families, summarizes the results of the focus groups and provides examples of the active strategies which all family members identified as being helpful in managing affective illness in the family.

There are, however, further recommendations which can be made in the areas of services, education, and policy-making:

1. In the area of services, adults with affective illness who have children should be identified. Such an identification would make it possible to offer psycho-educational service programs designed to assist families in understanding affective illness, in exploring its impact on families, and in suggesting methods to manage and cope with the illness. Such a program should allow families to mix and match proactive services to their specific needs. Further, it should implement a linking of services such as in-home homemakers, parenting coaches, family doctors, psychiatrists, self-help groups, and telephone support lines.

2. In the area of education, training programs which focus on a family-centred approach to care should be developed for health professionals. Further, educational tools to assist family members in understanding and coping with affective disorders should be developed. And, finally, public-education programs (such as telephone

information lines and programs on television dealing with depression) should be enhanced.

3. In the area of policy-making, the policy for the remuneration of physicians should be re-examined and alternatives to the fee-for-service model—which would allow for comprehensive family care—should be explored. Further, funding mechanisms need to be put into place in order to support more self-help groups for families and consumers.

This study highlights the need to consider the whole family context in the treatment and management of affective illness and supports the importance of involving the perspectives of all the stakeholders in conducting research, in planning services, and in designing policy and program interventions.

RÉSUMÉ

Cette étude explore les besoins de service des familles avec un parent souffrant d'une maladie affective. Des groupes de discussion et des entrevues individuelles ont été menés dans des lieux sélectionnés à travers le Canada avec des personnes ayant un trouble affectif, leur partenaire et leurs enfants adultes. Au total, 67 personnes ont été recrutées.

Les intervenants et intervenantes des mêmes lieux ont reçu un questionnaire par la poste demandant de l'information au sujet des besoins de ces familles, du rôle des intervenants et intervenantes et de ce qui les empêchaient ou les aidait à répondre aux besoins des familles. Au total, 419 intervenants et intervenantes ont participé à cette étude.

Les besoins identifiés par les familles et ceux identifiés par les intervenants et intervenantes ont été les mêmes. Cependant, il y a encore un grand écart entre la connaissance des besoins et la satisfaction de ceux-ci. Les résultats de cette étude identifient les lacunes des services offerts et donnent des recommandations pour des changements à l'égard des services, de l'éducation et des politiques.

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