

## **FOUR TYPES OF FAMILY INVOLVEMENT OVER THE COURSE OF SEVERE MENTAL ILLNESS: AN EXPLORATORY STUDY**

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### **ABSTRACT**

Little is known about the long-term involvement of families in the life of persons suffering from severe psychiatric disorders. The trajectories of 80 young adults are drawn in this study to determine social networks, service utilization patterns, and family involvement type. Findings indicate that, for community-living patients, family involvement type is a key adaptation factor.

### **INTRODUCTION**

Family members usually are present at the onset of an individual's severe psychiatric disorder, but the different levels of involvement that they maintain over the course of illness and the impact of these different levels of involvement on the individual have not yet been well documented (Brekker & Mathiesen, 1995; Carpentier, Lesage, & White, 1999; Cohler & Beeler, 1996; Lefley, 1996; Terkelsen, 1987). Some families are able to provide shelter for many years following the onset of severe symptoms. Other families, because of limited resources or other significant concerns, are in no position to contribute in any way to the long-term care of their mentally disordered relatives (Tausig, 1994). Between these two extremes, families can adopt a wide range of relational strategies. In many instances, families often remain involved in the lives of their ill relatives and represent a major source of support for them – even though the individuals no longer live with their families (Fisher, Tessler, Manderscheid, & Sommers, 1992; Carpentier, Lesage, Goulet, Lalonde, & Renaud, 1992; Tessler & Goldman, 1982).

Social support networks do not arise in a vacuum; they result from numerous personal, organizational, and social dynamics which affect the development of human relationships (Vaux, 1988; Sorensen, 1994). It has been determined by numerous studies that the social network of those suffering from severe psychiatric disorders are relatively small and consist mainly of family members (Albert, Becker, McCrone, & Thornicroft, 1998; Cohen & Sokolovsky, 1978; Macdonald, Hayes, & Baglioni, 2000). Family involvement is probably a factor that significantly influences the configuration of the social network of psychiatric patients. Indeed, the configuration of a patient's social network depends largely on the presence of the family and on its size, ability to assist the patient, and degree of openness to outside resources.

A number of studies have demonstrated an association between the dimensions of patients' social networks and their social adjustment or use of psychiatric services. For example, network size (i.e., the number of individuals with whom the caregiver is in contact) has been shown to be inversely proportional to frequency of hospitalization (Albert et al., 1998; Becker et al., 1997; Cohen & Sokolovsky 1978). High network density (i.e., the

degree of interrelationship between network members) has been linked to psychopathology (Mueller, 1980) but also to greater possibilities for co-ordinating action and increasing the supportive capacity of the network (Wellman, 1981). Furthermore, networks consisting of non-family members have proved able to offer better social support and also might be associated with more positive prognoses among persons with severe psychiatric disorders (Erickson, Beiser, & Iacono, 1998). Taking network measures and patients' residential situations into account, Salokangas (1997) demonstrated that living situation – especially cohabitation with a spouse or parents – significantly affected the psychiatric trajectory. A certain number of studies have taken patients' residences into account at various points along the illness trajectory (Brekker & Mathiesen, 1995; Brown & Birtwistle, 1998), although this factor represents a very incomplete measure of family involvement over long periods. However, one aspect that remains infrequently explored involves the restructuring of the patient's social network, including the rehabilitation of support skills, when the family distances itself from its ill relative.

Another less-explored dimension concerns the way in which families endorse the care mandate, orient their strategies, and define their obligations or level of responsibility towards their ill relatives (Finch, 1989). Karp and Watts-Roy (1999) observed that all the caregivers in their sample felt a strong sense of obligation to take care of their ill relatives at the onset of symptoms, but that this initial commitment diminished in intensity, especially when parents felt "that their efforts to care [were] ineffective, their own health [was] seriously jeopardized, or their sense of identity [was] in danger of obliteration" (p. 486). Other researchers have suggested that families had an "individual" or "collective" orientation, characterized by a strong sense of responsibility regarding their ill relatives' future (Pyke & Bengtson, 1996; Triandis, 1989). In mental health care research it has been observed that, compared with Caucasians, ethnic minorities often provided care on a more informal basis, lived with their ill relatives for a longer period of time, were more likely to rely on parents or children for support, and relied less on professionals (Brekker & Mathiesen, 1995; Horwitz, 1999; Kim & McKenry, 1998). Communities that have been in North America longer tended to have a more "individual" orientation, in that families were less involved in care and more readily agreed to delegate care-related tasks to professional services.

Structural and cultural dimensions of the trajectory of mental illness rarely have been investigated simultaneously. In my opinion, policies that focus on maintaining the individual in the community should encompass analysis of social integration processes and, more specifically, an understanding of the relationship between family context and individuals' adjustment within their immediate surroundings.

Several studies based on longitudinal data have described various patterns of schizophrenia (Heiden & Häfner, 2000; Ram, Bromet, & Eaton, 1992). Although the subject is open to debate (Roberts & Wolfson, 2004), it generally is accepted that as many as 68% of persons with schizophrenia will recover or improve significantly (Harding, Brooks, Ashikaga, Strauss, & Breier, 1987; Harrison et al., 2001). A great many factors intervene in the trajectory of persons with severe psychiatric disorders, including degree of patient's disability, developmental aspects of the illness, treatment resistance (McGlashan, 1988; Thara, Henrietta, Joseph, Rajkumar, & Eaton, 1994), strategies employed by professionals, treatment methods, organization of care (Amadeo, Zambello, Tansella, & Thornicroft, 2001; Cook & Wright, 1995), and societal response to the illness (Horwitz, 1982). However, it also has been suggested that the patient's social support network could be a significant factor affecting the course of mental illness (Pescosolido, 1992). Despite the

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interest in adopting a biopsychosocial orientation in the study of various processes linked to the issue of mental health, the analysis of social factors clearly has been neglected and the dominant paradigm in psychiatry-related research still regards interpretative analysis with suspicion (Corin & Lauzon 1992; Erickson, Beiser, Iacono, Fleming, & Lin, 1989; Pilgrim, 2002). Nonetheless, I believe that qualitative research can be very helpful in areas where little is known and hypotheses are difficult to generate.

One of the analytical methods favoured over the past few years in the study of health-related behaviours involves using a social network approach. This approach is based on the analysis of relational data (i.e., the strength of ties, the network's size, density, and homogeneity) rather than the actor's attributes (i.e., gender, age, social class). The network approach can easily be combined with qualitative approaches (Bazeley, 2003; Lazega, 1998); however, despite the fact that a growing number of researchers feel that the more qualitative aspects of the ties forming support systems should be considered (Brunt & Hansson, 2002; Randolph, 1998), such an integration of methodologies is uncommon in the field of mental health.

The purpose of this exploratory study, then, was to examine various network measures, taking type of family involvement into account. The objectives were threefold: (a) to determine type of family involvement over the course of illness of severely mentally disordered individuals; (b) to explore the long-term effect of family involvement on patient's social network configuration; and (c) to examine the association between family involvement and adaptive characteristics of those suffering from psychiatric disorders in terms of patient's use of services, perception of social support, and social integration.

## METHOD

This study was a sequel to a first phase of analysis, which identified two important variables for understanding the trajectory of severely mentally ill patients: (a) an estimation of the beginning of their illnesses, marked by their entry into the care process; and (b) a measure of network cohesion, drawn from the processes which led to their first hospitalizations. The study followed a mixed methodology design, which included quantitative measures and content analysis (Bazeley, 2003). The findings in this study were derived from a consideration of the time period following the patients' first hospitalizations for psychiatric reasons.

### Sampling Strategy and Description of Respondents

The sample for this study consisted of 80 severely mentally disordered outpatients. First, patients were recruited from the outpatient registry of a large psychiatric hospital in Montreal and then, with their consent, attempts were made to reach their families. The patients had a mean age of 28 years. The majority were men (61.3%), one quarter of the sample derived from immigrant families, 58 patients (72.5%) had been diagnosed with schizophrenia and 22 (27.5%) with affective psychosis (Carpentier & White, 2002).

### Data Collection and Analysis

Given the retrospective nature of the study, it was important to diversify data sources. To this end, a semi-structured interview was conducted with the patients and a complete review of their medical records was undertaken. These included numerous reports by various stakeholders, physicians, psychologists, social workers, and nurses. Then, with the patients' consent, family members also were interviewed. The 48 family members were distributed

as follows: 22 mothers, 4 fathers, 11 couples (both parents), 8 spouses, 2 siblings, and 1 aunt. Based on these varied information sources, an overall family history was reconstructed that served as a basis for qualitative analysis.

Data garnered from interviewing the patients and examining their medical records were reconstituted to identify the fundamental concepts for this analysis. Data from the interviews with family members served mainly to provide more comprehensive documentation of the processes related to their involvement. All qualitative data collected, whether through interviews or documentation, were re-transcribed as a family history in the manner of the narrative approach (Lieblich, Tuval-Mashiach, & Zilber, 1998). The raw material, averaging 20 pages in length for each case, was reconstituted within a synthetic "history" representing the experiences of the families and patients. Furthermore, the interviews and case notes were analyzed for thematic content in order to determine key concepts under study (initial unusual behaviour, patterns of interaction between patient and family members, family closeness, family involvement, family tensions, and family cultural value system). Lastly, quantitative data (network dimensions, social support measures, scales) were processed using various statistical procedures. Differences between subgroups were analyzed via Oneway ANOVA and Chi-square tests.

### Definition of Variables

In order to accomplish the three objectives identified for this study—determining the type of family involvement over the course of illness of severely mentally disordered individuals, exploring the long-term effect of family involvement on patient's social network configuration, and examining the association between family involvement and adaptive characteristics in terms of patient's use of services, perception of social support, and social integration—the data collected and analysed were organized under seven variables: (a) family involvement over the trajectory of the illness, (b) initial unusual behaviour, (c) primary social network at time of first hospitalization, (d) social support network at time of interview, (e) service utilization throughout the trajectory, (f) social adjustment at time of interview, and (g) independent daily living skills. These variables were constituted as follows:

*Type of family involvement over the trajectory* was determined based on systematic identification of the patient's place of residence and on continuity of support offered by family members. This involved documenting the interactions between family and patient, which included the transfer of resources and the provision of support through crisis situations.

*Initial unusual behaviour (onset)*—as perceived by the family or other social actors—was used to document the preliminary manifestations of illness, based on the work of Perrucci and Targ (1982), and thus the beginning of the patient's illness trajectory. Initial unusual behaviour can assume various forms, such as anxiety, depression, lack of motivation, or socially inappropriate behaviour (Carpentier et al., 1999). The time interval between onset and interview spanned an average of 8.6 years.

*Patients' primary social network* (Dykstra, 1990) *at the time of first hospitalization* was defined as those persons closely associated with patients and intimately involved in their activities of daily living and in decisions regarding psychiatric service utilization. At onset of illness, these networks had an average size of 2.6 actors (density = 0.6) and comprised primarily family members (86.6%). Density was calculated as the average number of linkages per person with others in the patient's network (Scott, 2000). For each

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network, degree of cohesion was determined based on two dimensions: the first was structural, corresponding to the presence of at least one clique within the network (relationship between a minimum of three actors), and the second provided a qualitative measure of the ties between members of the primary network, that is, a positive and constructive relationship between actors (for further details, see Carpentier & White, 2002). Of the networks, 44 were considered cohesive, and 36 were less so.

*The social support network at time of interview* was determined by the question: "Can you tell me who the most important people in your life are?" For each actor identified, the patient then specified whether the individual maintained ties with the other members of the network and, if so, the frequency of contacts. On average, networks at time of interview consisted of 6.5 actors (density = 0.38), of which 49.6% were family members, 26.9% were professionals, and 23.4% were significant others (e.g., friends, neighbours). Once the actors were identified, social support was assessed via a three-part question—To what extent does this person: (a) give you emotional support, (b) help you cope with daily life, and (c) enable you to meet other people? Each part of this question was coded according to the presence/absence of support on the basis of a yes/no answer.

*Service utilization throughout the trajectory* was identified through an examination of data on the use of professional resources provided by the archives department. Data on duration of use were obtained for six types of services: (a) emergency, (b) hospitalization, (c) outpatient clinic, (d) psychosocial follow-up, (e) group therapy, and (f) housing.

*Social adjustment at time of interview* was determined for each patient by obtaining data regarding changes in marital status, employment, and residential mobility.

*Independent daily living skills* were estimated by an adapted version of a scale used to estimate the patient's level of integration in the community. The questionnaire in this case used 65 items to assess patient behaviours in and attitudes towards the areas of recreation, job search, movement from place to place, personal finances, health, and daily living. The internal consistency of the subscales has a Cronbach's  $\alpha$  ranging from .47 to .72; test-retest reliability coefficients range from .67 to .90. The construct validity was further confirmed by factorial analysis and convergent validity. The reliability and validity of the scale have been extensively evaluated; satisfactory results have been obtained in this regard (Cyr, Toupin, & Lesage, 1993).

#### RESULTS

Four types of family involvement (FI) were identified by examining the data and analysis in light of the seven variables discussed. In the first type, families cohabited with their ill relatives throughout the observation period (from moment of determination of unusual behaviour to the time of interviews). In the second type, the patients no longer cohabited with their families, but maintained close ties with them. In the third type, family involvement varied—that is, patients received support and/or were housed intermittently. And, in the fourth type, families had broken off ties with their ill relatives and maintained very little or no contact with them.

Table 1 gives the number of patients per FI type. It was possible to meet most of the families in each category—even for Type 4 families, where parents essentially maintained no more than sporadic telephone contact with their ill relatives. Two families refused to participate in the study. No statistically significant difference across FI types was noted with respect to length of observation period.

**TABLE 1**  
**Four Types of Family Involvement**

	Number of patients by type of family involvement	Number of families met	Observation period (interval between first signs of unusual behaviour and time of interview)	
	n (%)	n (%)	years	(s.d.)
Type 1: Stable relationship involving cohabitation	24 (30.0)	13 (54.2)	7.4	(3.91)
Type 2: Maintenance of relationship after departure	28 (35.0)	19 (67.9)	8.2	(3.70)
Type 3: Unstable relationship	13 (16.3)	9 (69.2)	10.0	(4.45)
Type 4: Deteriorating relationship	15 (18.7)	7 (47.7)	9.9	(4.68)

By taking into account sociodemographic, clinical, and social network data pertaining to the individual at the beginning of the trajectory (Table 2) and those obtained through measures used at the time of the interview (Table 3), it was possible to organize the material gathered in this study into the identified four FI types. Using this organizational framework resulted in two outcomes: (a) the first objective of this study—determining the type of family involvement over the course of illness of severely mentally disordered individuals—was accomplished; and (b) preliminary steps were taken to fulfill the study's second and third objectives—exploring the long-term effect of family involvement on patients' social network configuration and examining the association between family involvement and adaptive characteristics of patients in terms of their use of services, perceptions of social support, and levels of social integration.

### **Type-1 Family Involvement**

Just under one-third of the overall study sample consisted of patients cohabiting with their families on an ongoing basis. Most of these individuals had tried living outside the family household and had lived in their own apartments for several weeks before returning to live with their parents. These families were involved on a daily basis at all levels, which included performing household chores and preparing meals. The families also stated that they devoted a lot of time to "keeping track" of their ill relatives and almost never left them alone in the house. Several parents expressed themselves in such a way as to leave no doubt regarding the importance of family support and their obligation to provide assistance. They stated that they were sceptical about housing resources and felt that only the family could provide beneficial support and supervision; they would consider resorting to other housing options to be an abandonment of their ill relatives. In their opinions, professionals were a necessary source of support, but they could not "provide love" and "take the time to listen."

Case #26. The patient came from a family of Italian origin and lived with his parents, two sisters, and a brother. The father was a gardener and owned his own business; the mother worked part-time in a factory, and the other children were active on the labour

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market. The family members made sure that the patient was never left alone. He had previously worked in the family business, but his lack of motivation brought this involvement to an end. The father clarified: "My son can come back to work with me whenever he wants to, but for the moment he shows no interest in doing so." The family reacted very negatively when the issue of placing the patient with a foster family was raised. However, the father found it hard to accept his son's illness: "He gets up at 10 o'clock and spends the day watching television . . . He never does anything around the house, never washes the floors or the dishes. When we ask him to do something, he says, 'Why should I be the one to do it?'" The father would not accept outside help, and admitted that he did not think much of the government or the hospital system and that he was very disappointed with his son's poor clinical progress. The mother always accompanied her son to the outpatient clinic.

**TABLE 2**  
**Four Types of Trajectories in Relation to Sociodemographic,**  
**Clinical and Social Network Variables at Onset of Illness (n = 80)**

		Type of Family Involvement				
		type 1 (n = 24)	type 2 (n = 28)	type 3 (n = 13)	type 4 (n = 15)	sig.
		<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	
<b>Sociodemographic and clinical aspects</b>						
Sex	Male	17 (70.8)	15 (53.3)	7 (53.8)	10 (66.7)	n.s.
	Female	7 (29.2)	13 (46.4)	6 (46.2)	5 (33.3)	
Education	Secondary V	13 (54.2)	17 (60.7)	8 (61.5)	9 (60.0)	n.s.
	College or higher	11 (45.8)	11 (39.3)	5 (38.5)	6 (40.0)	
Ethnic community	French-speaking					p < .001
	Quebecer	10 (41.7)	23 (82.1)	13 (100.0)	14 (93.3)	
	Other	14 (58.3)	5 (17.9)	0 (0)	1 (6.7)	
Diagnosis	Schizophrenia	20 (83.3)	19 (67.9)	7 (53.8)	12 (80.0)	n.s.
	Major affective disorder	4 (16.7)	9 (32.1)	6 (46.2)	3 (20.0)	
<b>Primary network</b>						
Cohesive		18 (75.0)	18 (64.3)	6 (46.2)	2 (13.3)	p < .001
Less cohesive		6 (25.0)	10 (35.7)	7 (53.8)	13 (86.7)	
		<i>mean (sd)</i>	<i>mean (sd)</i>	<i>mean (sd)</i>	<i>mean (sd)</i>	
Size of primary network		3.25 (1.39)	3.14 (1.20)	2.69 (1.10)	2.60 (1.54)	n.s.
Family		2.92 (1.10)	2.75 (1.17)	2.23 (1.09)	2.13 (1.35)	p < .05
Others		.33 (0.70)	.39 (0.56)	.46 (0.51)	.47 (0.83)	n.s.
Density		.74 (0.37)	.65 (0.41)	.56 (0.42)	.31 (0.39)	p < .05

**TABLE 3**  
**Four Types of Trajectories in Relation to Network, Service Utilization**  
**and Social Adjustment Variables at Time of Interview (n = 80)**

		Type of Family Involvement				sig.
		type 1 (n = 24)	type 2 (n = 28)	type 3 (n = 13)	type 4 (n = 15)	
		mean (sd)	mean (sd)	mean (sd)	mean (sd)	
Patient's social network size		5.17 (1.99)	7.50 (2.44)	6.85 (2.76)	6.20 (3.07)	p < .01
Number of family members		3.00 (1.44)	3.85 (1.77)	3.07 (1.70)	2.41 (2.29)	n.s.
Number of professionals		1.25 (1.03)	1.93 (1.05)	2.00 (1.15)	1.93 (0.79)	p < .05
Number of other actors		.92 (1.05)	1.72 (1.32)	1.76 (1.53)	1.86 (2.32)	n.s.
Patient's social network density		.46 (0.30)	.38 (.017)	.29 (0.16)	.38 (0.13)	n.s.
Social support	Emotional	1.66 (1.90)	3.03 (1.73)	3.46 (3.17)	2.53 (1.76)	p < .05
	Instrumental	1.75 (1.18)	2.10 (1.91)	1.76 (1.42)	1.13 (1.35)	n.s.
	Socialization	.58 (0.82)	.92 (1.38)	1.0 (1.41)	.66 (1.11)	n.s.
<b>Use of services</b>						
Visits to emergency room		1.75 (1.8)	2.79 (5.2)	9.15 (13.4)	2.87 (3.5)	p < .01
Number of hospitalizations		2.95 (1.96)	2.89 (1.96)	5.15 (3.62)	4.93 (2.93)	p < .01
Number of months hospitalization		6.1 (9.62)	5.4 (4.81)	10.59 (8.87)	25.45 (32.7)	p < .001
Number of months of outpatient clinic		41.0 (30.2)	49.5 (31.5)	45.0 (32.4)	43.9 (25.2)	n.s.
Number of months of psychosocial follow-up		22.3 (27.6)	31.5 (26.8)	29.7 (27.5)	40.5 (38.5)	n.s.
Number of months in working group		3.8 (11.3)	5.6 (9.8)	1.2 (3.02)	7.4 (13.6)	n.s.
Number of months of use of housing resources		0 (0)	18.9 (27.9)	16.6 (23.5)	31.7 (31.3)	p < .001
		n (%)	n (%)	n (%)	n (%)	
<b>Social adjustment</b>						
Marital status	Single/separated	24 (100.0)	19 (67.9)	10 (76.9)	11 (73.3)	p < .05
	Living with spouse	0 (0)	9 (32.1)	3 (23.0)	4 (26.7)	
Number of patients currently employed		7 (29.2)	16 (57.1)	1 (7.7)	3 (20.0)	p < .01
Number of patients previously employed		21 (87.5)	25 (89.3)	6 (46.2)	11 (73.3)	p < .01
		mean (sd)	mean (sd)	mean (sd)	mean (sd)	
Total number of months ever worked by patient		35.7 (34.5)	62.2 (60.0)	23.6 (39.9)	25.5 (28.7)	p < .05
Number of places ever lived in by patient		2.1 (1.27)	3.9 (1.77)	7.9 (2.96)	8.5 (4.51)	p < .001
Independent living skills scale		.63 (0.19)	.79 (0.16)	.59 (0.17)	.68 (0.17)	p < .01



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The various measures associated with the Type-1 FI profile are distinct in several ways at the beginning of the trajectory (Table 2). Most families belonged to cultural communities other than French-speaking Quebecer (58%,  $\chi^2 = 22.0$ ,  $df. = 3$ ;  $P < 0.001$ ). The patients' primary social networks were large in size (3.25 actors, *n.s.*), high-density (0.74,  $F = 3.68$ ,  $df. = 3$ ;  $P < 0.05$ ), and cohesive (in 75% of cases,  $\chi^2 = 15.78$ ,  $df. = 3$ ;  $P < 0.001$ ). The patients' support networks at the time of interview (Table 3) were the smallest across all the FI profiles (5.17,  $F = 3.90$ ,  $df. = 3$ ;  $P < 0.01$ ): they included few professionals (1.25,  $F = 2.62$ ,  $df. = 3$ ;  $P < 0.05$ ) and the lowest number of persons providing emotional support (1.66,  $F = 2.76$ ,  $df. = 3$ ;  $P < 0.05$ ). With respect to services, these patients visited hospital emergency less often (1.75 times,  $F = 4.08$ ,  $df. = 3$ ;  $P < 0.01$ ) and were hospitalized less frequently (2.95 times,  $F = 4.37$ ,  $df. = 3$ ;  $P < 0.01$ ). All of these patients also had remained single and scored low on the independent living skills scale (mean = 0.63,  $F = 5.56$ ,  $df. = 3$ ;  $P < 0.01$ ).

### Type-2 Family Involvement

More than a third of the individuals in the study had families who continued to be involved in their lives after they had left home. At the time of the interviews, these patients lived alone (9), with a common-law spouse (9), with a roommate (1), with another family member (1), in supervised apartments (4), or in foster homes (4). Analyses indicated that most families interviewed had contacted various social actors and their discussions had led them to become progressively aware of the need to make decisions and take action to reduce the burden on the family and promote their relatives' independence in a gradual way. This period of dialogue appeared to be conducive to adaptation and a possible change of attitude on the part of the families in question. Through these discussions with relatives, friends, and professionals, families developed a more long-term strategy. With the eventual development of a co-operative relationship with professionals, families were able to devise a concerted action plan. The transition from living at home to living independently was often the subject of much discussion between the patient, professionals, and the family. Contact between the actors allowed them to predict problematic periods, and action was taken to deal with any possible difficulties.

Case #9. The patient was hospitalized for several months following a very severe psychotic episode. This period allowed the family to discuss the situation with other family members and professionals. The father's brother, a school chaplain who also worked with people with mental health problems, convinced the parents that the situation was serious and that, if no action was taken, the patient could become locked into a pattern of repeated hospitalization. After consulting a professional team which specialized in mental health treatment, the parents opted for a strategy that would help the patient become independent. A step-by-step approach was suggested and the most appropriate type of resource to use was the subject of lengthy discussion. When the patient left the hospital, he was first directed to a foster home, where he lived for seven years; he then went to live on his own in a supervised apartment. Since he left home, his parents have maintained a very good relationship with him and regularly welcome him to the family home for visits. In addition, the parents obtained information about mental health problems by becoming actively involved in a self-help group. The family felt very encouraged, as their son had never been rehospitalized and planned to return to school. The family were optimistic about the future.

At the beginning of the trajectory, most patient networks associated with this FI type were cohesive (64.3%) but less dense than was the case with Type 1 (*n.s.*). At the time of the interview, these networks were the largest of all the FI types (7.5 actors,  $F = 3.9$ ,  $df. =$

3;  $P < 0.01$ ) and the hospitalization rate for these patients was the lowest in terms of both frequency ( $F = 4.37$ ,  $df. = 3$ ;  $P < 0.01$ ) and duration ( $F = 6.12$ ,  $df. = 3$ ;  $P < 0.001$ ). The ratio between number of months of outpatient clinic follow-up (49.5 months) and length of observation period (8.2 years) indicated that these patients visited outpatient clinics more regularly than did patients in the other groups (ratio for Types 1 to 4: .71, .81, .72, and .75, n.s.). Many of them lived with a partner (32.1%), appeared to be more active on the labour market (57.1% currently employed,  $\chi^2 = 12.29$ ,  $df. = 3$ ;  $P < 0.01$ ), and participated more actively in the return-to-work program offered by professional services (mean = 5.6 months, n.s.). They also scored higher on the independent living skills scale (mean = 0.79,  $F = 5.56$ ,  $df. = 3$ ;  $P < 0.01$ ).

### Type-3 Family Involvement

A certain number of families found it difficult to remain involved with their ill relatives. They went through repeated cycles of unconditional involvement, followed by exhaustion, and then by virtual abandonment. Interviews with these families were very emotional: sometimes parents expressed confidence as to their ability to help; other times they expressed great ambivalence, stating that they felt very burdened by their responsibilities. One mother stated: "My daughter is my whole life . . . I would do anything to help her get better . . . I will never abandon her." In this group, we observed a higher frequency of unstable situations involving trouble with the law, suicide attempts, and family violence. Such events often caused the families to distance themselves; however, the parents' sense of guilt, their hopes for the patients' recovery, or their desire to help led them to re-establish contact and welcome the patients back into the home.

Case #29. A single mother maintained a varied level of involvement in her daughter's life over the 13 years of her illness. Reflecting upon the onset of illness and the gravity of the situation, the mother admitted that she had been slow to react and seek help. She discussed her behaviour towards her daughter before the illness: "I spoiled her too much; I asked practically nothing of her, she did what she wanted." Worn out from supporting her daughter for many years, the mother admitted: "If I had known what was going to happen when this all began, I would have killed myself." Since the onset of illness, the daughter has lived with her mother three times. In between, she shared an apartment with a student for two years, and lived for one with a boyfriend who was addicted to several substances and had severe mental health problems of his own. During this period, the mother was totally devoted to her daughter and visited her apartment to perform many daily living tasks. In this context, a violent outburst against the mother caused the relationship to break off completely and the daughter was hospitalized. After several months of negotiations, the mother agreed to allow the daughter to live at home again. She imposed new conditions and sought to make access to services easier, in particular by moving close to the outpatient clinic and a fitness centre. The mother also negotiated financial conditions and arrangements regarding her daughter's social life (time-limited visits by her friends), thus allowing the daughter to integrate more easily and guarantee some continuity in family life.

The Type-3 FI profile was characterized by less cohesive (53.8%), low-density networks (mean = 0.56) at the earliest point in the trajectory. At time of interview, the patients' social networks had the lowest density across all FI types (mean = .29, n.s.) and included a larger proportion of professionals (2.0,  $F = 2.62$ ,  $df. = 3$ ;  $P < 0.05$ ). Conversely, patients perceived these networks as very supportive, especially regarding emotional support (mean = 3.46,  $F = 2.76$ ,  $df. = 3$ ;  $P < 0.05$ ), although it should be noted that this support was provided primarily by sub-groups of friends. Regarding service utilization, these patients visited hospital emergency most often (9.15 times,  $F = 4.08$ ,  $df. = 3$ ;  $P < 0.01$ ),

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were hospitalized most frequently (5.15 times,  $F = 4.37$ ,  $df. = 3$ ;  $P < 0.01$ ), and were less conscientious about visiting the outpatient clinic (ratio of .72, n.s.). In addition, these patients had difficulty participating in social life, were fairly inactive on the labour market (7.7%,  $\chi^2 = 12.29$ ,  $df. = 3$ ;  $P < 0.01$ ), and changed residences frequently (7.9 times,  $F = 25.92$ ,  $df. = 3$ ;  $P < 0.001$ ). They also scored lowest on the independent living skills scale (mean = 0.59,  $F = 5.56$ ,  $df. = 3$ ;  $P < 0.01$ ).

#### Type-4 Family Involvement

Fifteen families had broken off contact with their ill relatives over the course of the observation period. Although some of these families had already begun distancing themselves while their ill relatives were adolescents, most did so after onset of illness. The economic situation of these families often was precarious; they lived in small apartments and did not hold stable jobs. A divorced mother living in a very small apartment in a poor neighbourhood declared that her son's psychiatric history did not surprise her: "I had two perfectly normal daughters, but ever since he was born, I knew that my son was going to have a lot of problems." This mother accepted more professional assistance because she felt her son's problems were too severe for her to deal with. Hence, lack of family involvement could be explained in part by poverty and a lack of resources, but other factors—including geographical distance after the family moved or the ill relative was transferred to another psychiatric institution, perceived danger or violence, long periods of institutionalization, state of health, death or advanced age of parents—also played a role and seemed to discourage maintenance of the relationship.

Case #8. The patient was hospitalized eight times in the past 14 years, the first few in a general hospital near the family home. The patient's state of health was considered very problematic (e.g., he ran away, was apprehended by the police and held in a detention centre). A court order was obtained to transfer the patient to a psychiatric hospital. This centre was located at the other end of town. The latest hospitalization lasted nearly 6 years and the parents gradually withdrew from the patient's network, at first owing to geographical distance and then also for health reasons. The father died a short time later and the mother lost mobility and limited her contact to two phone calls per year.

At the beginning of the trajectory, the primary networks of the patients in this group were the smallest across all FI profiles (mean = 2.6 actors, n.s.), had the lowest density (0.31,  $F = 3.68$ ,  $df. = 3$ ;  $P < 0.05$ ) and appeared less cohesive (86.7%,  $\chi^2 = 15.78$ ,  $df. = 3$ ;  $P < 0.001$ ). At the time of the interviews, networks consisted of a few family members (spouses, brothers, or sisters) and mostly non-family actors (professionals and friends). These patients were hospitalized very frequently (4.93 times,  $F = 4.37$ ,  $df. = 3$ ;  $P < 0.01$ ), had the longest hospitalizations (mean = 25.45 months,  $F = 6.12$ ,  $df. = 3$ ;  $P < 0.001$ ), made greater use of housing services (mean = 31.7 months,  $F = 6.13$ ,  $df. = 3$ ;  $P < 0.001$ ), experienced difficulty integrating into the labour market, and had the highest levels of residential mobility across all FI types (8.5 moves,  $F = 25.92$ ,  $df. = 3$ ;  $P < 0.001$ ).

#### DISCUSSION

The purpose of this study was to identify FI types and explore their potential effects on the trajectory of severely mentally disordered persons. This is far from a linear process: family involvement influences the configuration of the patient's network, which in turn influences service use and/or social adjustment. Complex patterns can emerge, depending on the evolution of the psychiatric symptoms or the involvement of different social actors. Intervention by a treatment team can provide family support programs which appear to

motivate parents to stay involved. Some treatment teams have more resources, which allow them to offer services, such as a job search program, which can help restore an individual's sense of dignity, and thus possibly motivate continued family involvement. The structure of the patient's network may therefore change according to the organizational conditions (introduction of the treatment team) that influence and act on FI type. Further, the relationship between FI, social network dimensions, and service utilization is likely to be complex and multi-directional.

In the simplified model used for this study, family involvement was emphasized and used as the organizing framework for discussion. Other sources of influence on the trajectory of severe mental illness were taken into account to the extent that information was available. From this model, four types of FI were identified. The first FI type covers families that cohabit continuously with their ill relatives. This type is associated with a trajectory that is rather favourable clinically, but more problematic socially. Although these patients are hospitalized much less frequently and use fewer professional support services, they appear to be less integrated into the community. The second FI type involves families that provide support to ill relatives who live independently. This type is associated with a low rate of hospitalization, greater utilization of outpatient services, and better social integration—and is probably the most favourable situation for the patients. Families that fall under the Type-3 FI profile have difficulty remaining involved. Over time, their relationships with their ill relatives remain unstable—which, in my opinion, gives rise to a problematic trajectory. This unstable situation does, however, allow patients to branch out socially and develop support ties outside the family. The fourth FI type encompasses families that are involved at the beginning of the trajectory but that gradually distance themselves. This is probably the most problematic trajectory, especially with respect to frequency of hospitalization and patient's social integration.

My findings are similar to those obtained in other studies (Horwitz, 1977; Pescosolido, 1992) in which researchers observed that neither structural nor cultural dimensions considered independently can account for the various processes associated with the psychiatric trajectory. Patients' social networks, which include a high proportion of family members at onset of illness, evolve partially in response to this initial configuration but also in relation to the organization of services, social context, and type of long-term family involvement. The extent of family involvement depends not only on the family's access to internal or external resources, but also on their cultural values. My observations correspond, in part, to the "individualism/collectivism" dichotomy (Pyke & Bengtson, 1996; Triandis, 1989) in that a high proportion of the families that fell within the Type-1 FI profile were culturally non-French-Canadian. From many standpoints, these families have adopted a collectivist orientation that favours long-term cohabitation, promotes values related to the provision of support, and advocates nearly unconditional devotion to their ill relatives. This family orientation is based, at least at the beginning of the trajectory, on a large-sized primary network. However, it would be inappropriate to associate the rest of the sample (i.e., Quebecers descending from French colonialists) with a purely individualist orientation. Most of the families in the study claimed to be very attached to their ill relatives, troubled by their state of health, and ready to do anything to help them. Such statements were uttered by family members in the Type-2 FI group and were common among those in the Type-3 group, although the latter lacked the resources to translate their intentions into actions. Early in the trajectory, networks associated with Type 3 are small and not very cohesive. This lack of cohesion is associated with communication difficulties, conflicts, and the weakness of regulatory mechanisms (that is, the social relationships

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based on informal norms that govern interpersonal relationships) (Carpentier & White, 2002).

Type-2 FI represents, in my opinion, an optimal situation which is characterized by a facilitating structure (cohesive, medium-density network), a willingness to assist the patients, and an assistance strategy based on a task-sharing model. The families acknowledge their limitations and leave specific—and possibly more specialized—tasks to professionals. Here, the notion of network density can enlighten us regarding certain aspects. High density (Type 1) leads network members to rely on one another and reduce access to new information; conversely, low density (Type 4) does not allow actions to be co-ordinated and reduces the family's ability to provide support (Perrucci & Targ, 1982; Wellman & Gulia, 1999). The average network density observed in Type-2 FI is more effective; it allows a high level of communication among network members, facilitates the establishment of links with outside actors, and reinforces the group's ability to take concerted and preventive action. This conclusion corresponds with the findings of Dozier, Harris, and Bergman (1987), who noted that medium-density networks were associated with fewer hospitalization days in a sample of young schizophrenic patients, and with those of Brekker and Mathiesen (1995), who observed that patients who did not cohabit with their families but maintained continuous contact with them were more active in the labour market and scored higher on the social functioning scale.

As many authors have already observed, the presence of a family network appears to be a important factor in the adaptation/adjustment of patients living in the community (Biegel, Sales, & Schulz, 1991; Macdonald, Hayes, & Baglioni, 2000; Tausig, O'Brien, & Subedi, 1992). However, families maintaining close ties can isolate or overprotect their ill relatives, thus discouraging them from living independently and hindering their social integration (Clausen & Huffine, 1975; Grusky, Tierney, Manderscheid, & Grusky, 1985). Consistent with the findings of other recent studies (Brekker & Mathieson, 1995; Brown & Birtwistle, 1998), this study does, in fact, confirm the importance of family involvement, but with the following qualifier: Families that are too closely involved appear to offer protection against hospitalization, but entrap their ill relatives and isolate them from the outside world by not allowing them to develop their independent living skills.

This study, however, refines certain well-known observations. For example, several past studies determined that network size was inversely proportional to frequency of hospitalization (Åberg-Wistedt, Cressell, Lidberg, Liljenberg, & Ösby, 1995; Becker et al., 1997; Fraser, Fraser, & Delewski, 1985); here, network size was associated with infrequent hospitalization only in the Type-2 FI group, and not in the Type-1 group. Regarding the homogeneity measure (diversity of relationships), like Tausig and colleagues (1992), I observed that networks made up almost exclusively of family members (Type 1) used formal care services with a lower intensity, and that networks with a low proportion of family members were heavy consumers of formal services. Conversely, Erickson and colleagues (1989) found heterogeneous networks to be associated with better prognoses. This is partially consistent with my observation that FI Types 2 and 3 are associated with heterogeneous networks; however, I noted that it is essentially when the family remains involved (Type 2) that the trajectory is favourable. Although the differences observed may have many origins related to sampling and patient characteristics, among others, I believe that they can be explained, at least in part, by FI type. I consider this to be an important aspect that, to date, has received little attention.

Type-3 FI is associated with a trajectory marked by frequent hospitalizations and very low patient scores on the independent living skills scale. Perhaps owing to the instability of

the relationship with their parents, these patients turn to friends for emotional support. Conversely, patients cohabiting with their families (Type 1) perceive significantly less emotional support from their networks. In my opinion, these conclusions do not appear unreasonable. It has already been observed that a certain distance from the family can be beneficial: emotional support is often incompatible with daily physical proximity, in which one must deal with the minor disagreements related to daily living (Corin & Lauzon, 1992; Hooley & Hiller, 1997).

Lastly, families belonging to the Type-4 FI group generally lacked social resources and, in some cases, had already distanced themselves somewhat from their ill relatives before the onset of their illnesses. At the time of first hospitalization, weak network cohesion was one more indicator of limited family resources and predicted a problematic trajectory for patients in this group. Networks with weak cohesion are associated with family withdrawal or difficulties maintaining continuous involvement. These networks are not in a position to implement long-term strategies, co-ordinate efforts, and steer patients towards a favourable psychiatric trajectory. Network cohesion can promote a protective effect, allow relationships to be maintained, and possibly contribute to patients' social adjustment (Carpentier & White, 2002).

As this is an exploratory study, its data must be interpreted with caution. The principal objective of this study was to explore types of long-term FI by way of a retrospective design. Hopefully, this study can be reproduced while improving several methodological aspects: (a) using a longitudinal design that would make it possible to conduct patient interviews at various points along the trajectory; (b) ensuring that families participate more actively; and (c) controlling for a greater number of factors which are already considered potential factors influencing the trajectory—including sociodemographic characteristics, clinical variables (e.g., premorbid conditions, diagnosis, severity of symptoms) and service organization.

In this study, the primary focus was the family and its long-term involvement, and only a limited number of related variables were considered. Controlling for a high number of factors requires a large sample and reduces the ability to conduct in-depth interviews. The use of a mixed methodology calls for a "trade-off" between extensiveness and intensiveness (Bazeley, 2003). Several concepts that I sought to develop in this study required a qualitative analysis of verbal or written data. However, I did not discount the fact that some of these data could be expressed in numeric form and thus facilitate statistical processing.

This study possesses several strong points, particularly the fact that it involved a sample that was relatively homogeneous in terms of age and diagnosis (young people with severe psychiatric disorders) and representative of patients registered with outpatient clinics part of a public, universal healthcare system. Lastly—and I find this point encouraging—I must point out that many of the findings generated by controlled studies do not contradict my findings. Rather, I feel that this study explored new avenues and made a significant contribution, especially with respect to families experiencing difficulty maintaining supportive relationships with their ill relatives.

## CONCLUSION

The analysis of family influence on the trajectories of persons with severe psychiatric disorders remains a sensitive subject. Historically speaking, studies generally have led researchers to consider the family to be a pathogenic entity (emphasizing pseudomutuality, double binds, or intrusiveness), and the same holds true for more recent works emphasizing

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family hostility and criticism (Carpentier, 2001). These studies, in part, help to perpetuate the idea that families generate an essentially negative effect on their ill relatives and do not lead to strong efforts to create a partnership between themselves and professionals. Following the example of a growing number of studies, however, I noted that families play a central supportive role in the community and can be an essential factor in the rehabilitation of their ill relatives. We must, however, acknowledge that families are far from homogeneous and that their values and resources can vary widely.

The identification of FI type has many implications. It allows us to recognize that families function in different ways and that other concerned parties must adapt to them and respect their values and standards. Under certain circumstances, professionals must actively assist families and even temporarily serve as substitutes for them until they regain their strength and adjust to their ill relatives. However, as much as possible, families must not be excluded from the relationships between the individuals and professionals. Maintenance of family ties is a very important part of the healing process, and reconstructing the support network becomes more difficult when families are absent (Breier & Strauss, 1984; Salokangas, 1996). This position differs from certain patient-centred programs that tend to discourage family contact (i.e., Beard, Propst, & Malamud, 1982; Dincin, 1995). This study indicates that a vast majority of families are involved with their ill relatives and suggests that a number of parents seek to do their best, even though they do not always possess the resources to maintain their involvement. Lastly, because of its retrospective nature and small number of subjects, this study remains exploratory. It nevertheless underscores the importance of pursuing research on the ways in which families influence the trajectory of care.

## RÉSUMÉ

Nous ne connaissons que peu de chose sur l'implication à long terme des familles de personnes souffrant de problèmes psychiatriques sévères. La trajectoire de 80 jeunes adultes est reconstituée permettant ainsi d'établir leur réseau social, leur utilisation des services et le type d'implication des familles. Les résultats démontrent que le type d'engagement familial est un facteur d'adaptation important pour le patient ou la patiente vivant dans la communauté.

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