

BEING THE CAREGIVER OF A PERSON WITH A MENTAL HEALTH PROBLEM

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ABSTRACT

Providing care to a friend or relative suffering from a mental health problem can affect the physical and mental health of the caregiver. In the Montreal Mental Health Survey, 405 caregivers of people suffering from such problems took part in a mail survey about their experiences. The goal of this article is to describe these caregiving experiences and to identify their predictors. Results show that seriousness of the care recipient's problem is a predictor of a negative caregiving appraisal, but much less so of a positive one. The caregiving context is decisive in relation to both the positive and negative aspects of the experience. A strong correlation is observed between the positive and negative aspects of the scale, indicating that the caregiving experience is not one-dimensional. On the contrary, it can be simultaneously burdensome and satisfying.

People with mental disorders are increasingly being treated outside institutions. Their families and friends are often called on to provide significant and continuous support, and to maintain links with numerous institutional and community assistance resources. This situation can have repercussions for the physical and mental health of the caregivers. Several studies of the consequences for caregivers and their families of providing care to people with mental disorders have noted a high level of psychological distress among caregivers, and even, in some cases, the presence of physical or mental problems (Falloon, Graham-Hole, & Woodroffe, 1993; Harvey, 2000; Perring, Twigg, & Atkin, 1990; Wittmund, Wilms, Mory, & Angermeyer, 2002). To assume this role, caregivers need support; however, this support remains mostly inaccessible and unavailable (Guberman, Maheu, & Maillé, 1993; Ministère de la Santé et des Services Sociaux du Québec, 2001).

To better evaluate the association between caregiving and psychological distress and to compensate for recognized limitations of the notion of "burden," Szmukler et al. (1996) developed a model describing the caregiving experience based on Lazarus and Folkman's stress-appraisal-coping paradigm (1984). This model is centred on the notion that caregivers appraise stressful events, in this instance their relative's or friend's mental disorder or the demands associated with caregiving. An appraisal of the stressful situation is influenced by mediating factors such as social support, family environment, and feeling of control. The outcome of this situation for a caregiver, in terms of physical or psychological morbidity, depends on the interaction between the caregiver's appraisal and his or her coping strategies. Szmukler et al. (1996) used this conceptual framework as the basis from which they developed and validated the Experience of Caregiving Inventory (ECI), designed to measure caregivers' appraisal of stressful events. They demonstrated that this instrument is an accurate predictor of psychological morbidity. Other studies using this measurement

scale have shown that the ECI, and especially its negative subscales, predict the psychological well-being of caregivers of people with mental illnesses better than measure of burden (Harvey, Burns, Fahy, Manley, & Tattan, 2001; Joyce, Leese, & Szmukler, 2000; Martens & Addington, 2001). Therefore, people for whom caregiving tends to be negative also experience greater psychological distress.

In a study of the predictors of the caregiving experience, Harvey et al. (2001) showed that the caregiver's appraisal is more negative when the care recipient is young and unemployed. Moreover, caregiving is perceived less positively when a patient has been suffering from the illness for a long time and does not function well socially. Another study using the ECI demonstrated that depressed and anxious behaviours in a care recipient are associated with the ECI's negative appraisal scales, as are the numerous tasks carried out by a caregiver (Tucker, Barker, & Gregoire, 1998). Moreover, several studies found that there is greater psychiatric morbidity among female than male caregivers in a caregiving situation (Wittmund et al., 2002; Yee & Schulz, 2000).

To better identify caregivers who are more likely to develop health problems, we set out to explore how they experience caregiving and what the predictors of the caregiving experience are. The goal of this article is to describe and evaluate caregivers' experience, using the instrument developed by Szmukler et al. (1996) with both its negative and positive scales, and to identify the predictors of this experience.

METHOD

Conceptual Model

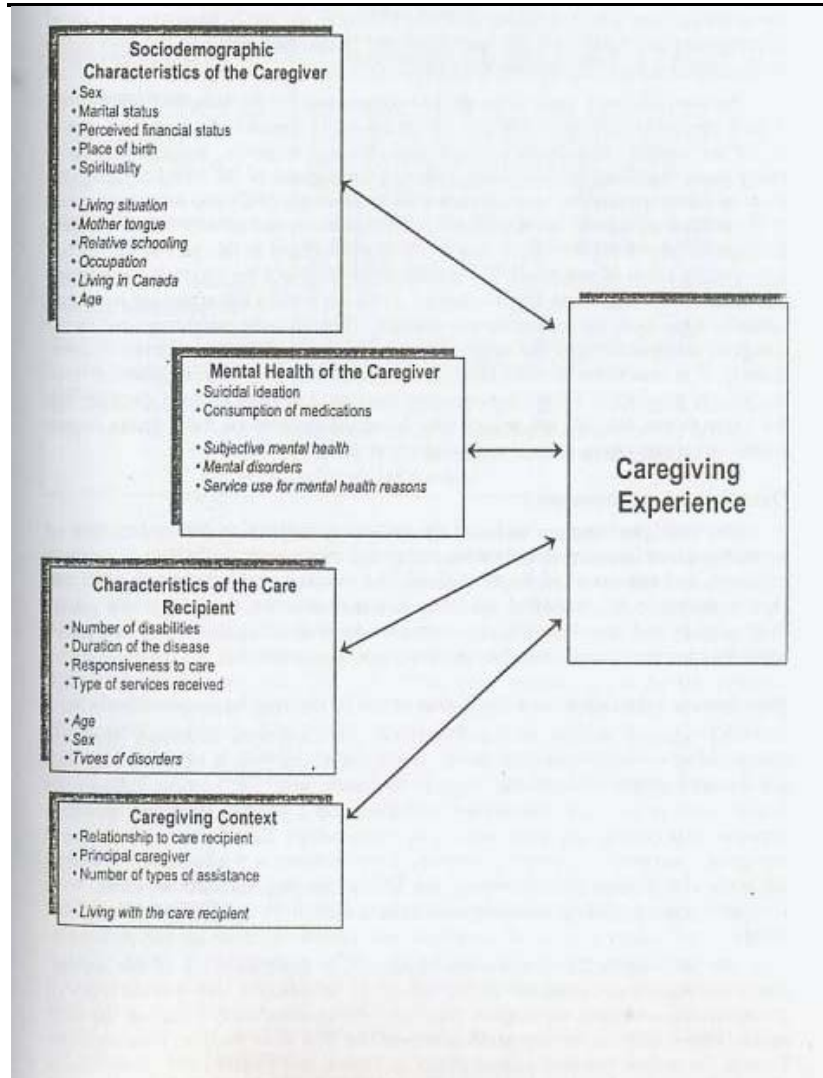
Our study measured a number of variables related to the caregiving experience in the literature, divided into four distinct blocks: sociodemographic characteristics of the caregiver, mental health characteristics of the caregiver, characteristics of the care recipient, and characteristics describing the caregiving context. Figure 1 presents the model we used to study the effects of the predictors of the caregiving experience, with a list of the variables included in each group.

Our choice of including the caregiver's mental health scale among the predictors of caregiving was based on the cross-sectional nature of the study, through which causal relationships between variables cannot be determined, and on the composition of the caregiving population under study, consisting of primary or secondary caregivers of people with various types of mental health problems. It is highly probable that, in this kind of study, in some cases the caregiver is connected to the patient because she or he has had similar problems and has developed a friendship through self-help groups, for example. We discuss the link between mental health variables and the caregiving experience below.

Study Context

The present study is based on data derived from a large-scale health survey conducted in Montreal in 1999. The main objective of the survey was to determine the prevalence of the most common mental disorders in the population and to identify informal caregivers. A two-phase sample design was used (Fournier, Lemoine, Poulin, Poirier, & Chevalier, 2001). First, a telephone survey was carried out with a probability sample of 4,704 respondents aged 18 years and over living in private households. Second, a total of 780 persons, or 17% of the study population, were identified during telephone interviews as caregivers who met study criteria (having

FIGURE 1
Model of the Predictors of the Caregiving Experience
(variables in italics not included in final model)



offered any kind of non-professional assistance to someone close to him or her at least once every 2 weeks during the last month), and were asked to complete a self-administered mail survey. In all, 405 informal caregivers returned a properly completed questionnaire, for a response rate of 51.9%. The caregiver component of the survey used a population approach, which can reach all individuals (whether they are primary or secondary caregivers) providing assistance to a friend or family member suffering from a mental health problem (Lavoie et al., 2002). Moreover, it looked

at caregivers of people with all types of mental health problems and not only those with severe and persistent mental disorders.

We used different types of weights to compensate for the sampling procedures. A first type of weighting, applied to the initial 4,704 respondents, meant we could adjust for unequal probabilities of selection, for non-response, and for inferences being made regarding the population. Then, a comparison of the weighted distributions of relevant variables was conducted for participants (405) and non-participants (375) in the mail survey. No significant difference was noted for any variable except for type of help provided, where slightly more participants in this part of the survey gave certain kinds of assistance. Several attempts to correct the situation were tested but without any significant improvements. Although certain discrepancies were statistically significant, no correction was brought. Therefore, the weighting used in the caregiver component was the same as that used in the telephone survey. Consequently, it is reasonable to think that this weighted sample is quite representative of the general population. Partial non-response rates were verified for each question and for every factor; they do not exceed 5%. More information on these facets is presented in the caregiving survey report (Lavoie et al., 2002).

Data Collection Instruments

The mail questionnaire included the following sections, in this order: type of assistance given (caregiving activities), caregiving experience, disabilities of the care recipient, and care received by the patient. The measurement instruments used and their provenance are presented in Table 1. Information on the caregiver's socio-demographic and mental health characteristics as well as on the context in which assistance is given was collected during the telephone interview.

Description, Adaptation, and Validation of the Caregiving Experience Scale

The original version of the Experience of Caregiving Inventory (ECI) is composed of 66 items grouped into 10 subscales, comprising 8 negative (difficult behaviours, negative symptoms, stigma, problems with the services, effects on family, need to back up, dependency, and loss) and 2 positive subscales (positive personal experiences and good aspects of relationship). Each question includes a choice of 5 answers (1 = *never*, 2 = *rarely*, 3 = *sometimes*, 4 = *often*, and 5 = *nearly always*). The internal consistency of the ECI in its original form is good, with Cronbach alpha scores for each subscale ranging from 0.74 to 0.91 (Szmukler et al., 1996).

The ECI was modified somewhat to adapt it to the framework of our survey. Since the study was conducted among caregivers of relatives who had all types of mental health problems, we adapted scale items by systematically replacing the term *mental illness* with the term *mental health problem*. The scale was also translated into French. To ensure question comparability in French and English, the questionnaire was back-translated. Answers to the French (302 respondents) and English (103 respondents) questionnaires were compared to identify any possible bias introduced in the translation. No significant differences were observed.

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TABLE 1
Instruments Used in the Self-Administered Questionnaire
and Their Provenance

Element Measured	Instrument and Provenance
For Caregivers	
Type of assistance provided (caregiving activities)	Questions developed based on the classification by Guberman, Maheu, & Maillé (1993): types of assistance provided during the last 4 weeks; 19 items
Caregiving experience	Caregiving experience scale, adapted from Szmukler et al. (1996): 66 items, 5 levels of response, 10 subscales (8 negative and 2 positive)
For Care Recipients	
Disabilities (activities done by the person receiving care)	From <i>Wisconsin Quality of Life, Family Questionnaire</i> by Becker, Diamond, & Sainfort (1994)
Care received	Canadian Study of Health and Aging Working Group (1994), modified: services received and perception of adequacy of services

Factor analyses were performed to verify the scale's construct validity within the context of this study. Some items had to be removed from the scale because they did not offer enough variation or show enough commonality with the subscales (< 0.30). Thus, the modified version of the scale includes only 45 of the 66 items in the original version, grouped into 8 subscales (7 negative and 1 positive). Despite these modifications, the final factorial structure is very close to that of the original scale. The 45-item scale accounts for 48% of the total variance (56% for the principal component analysis versus 60% in Szmukler's original version), which is evidence of the scale's construct validity within the specific context of this survey. All factors, except for *Stigma*, presented good internal consistency. Finally, the scale's factorial structure and the Cronbach alpha values for each factor are similar for francophones and anglophones (see Table 3 for Cronbach alpha values).

Analyses

To assess the effect of predictors of the caregiving experience, linear regression analyses of each negative subscale in the modified ECI, the combined negative subscales, and the positive subscale were performed using SPSS version 10.1. First, to gain a better understanding of the predictors, linear regression analyses were conducted separately within each block. Predictors that were not significant for any dependent variables (i.e., all subscales of the ECI) were dropped. The remaining variables were then combined into a full model using a block sequential logic. These variables are listed in Figure 1.

The caregivers' characteristics blocks (sociodemographic and mental health) were introduced first, to determine and control the effects of the caregiver variables. Then, the blocks *Characteristics of the care recipient* and *Caregiving context* were

introduced. Finally, Pearson's correlation test was used to assess associations between the instrument's negative and positive aspects.

RESULTS

Description of the Population

Table 2 presents the characteristics of the caregivers, care recipients, and context in which assistance is provided. In one third of cases, the caregiver was the principal caregiver; in most cases (82%), the caregiver did not live with the care recipient. The

TABLE 2
Characteristics of the Caregiver and Care Recipient,
and of the Caregiving Context
(N = 405)

Variable	%	Variable	%	
Sociodemographic Characteristics of the Caregiver		Characteristics of the Care Recipient		
Sex of caregiver:		Number of disabilities:		
Male	42	None	43	
Female	58	1 or 2	38	
		3 or more	19	
Marital status:		Duration of the disorder:		
Married/common law	46	Less than 5 years	28	
Separated/divorced/widowed	19	5 to 19 years	26	
Single	35	20 years and over	11	
		Unknown	35	
Perceived financial status:		Responsiveness to care:		
Comfortable	18	Accepts assistance	76	
Sufficient	67	Refuses assistance	24	
Poor/very poor	15			
Place of birth:		Type of services received:		
Canada	80	No services	20	
Outside Canada	20	Professional services only	42	
		Intensive services	38	
Spirituality:				
Important	77			
Not important	23			
<i>Occupation*:</i>		<i>Sex of care recipient*:</i>		
Active	22	Male	46	
Inactive	78	Female	54	
<i>Living situation*:</i>		<i>Type of disorder*:</i>		
Lives alone	25	Depressive	37	
Couple, with no children	18	Substance abuse	21	
Family with children	43	Anxiety/psycho. or bipolar	23	
Co-tenant or other	14	Others	17	
<i>Mother tongue*:</i>				
French	65			
English	17			
Other	18			
Mental Health of the Caregiver		Caregiving Context		

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Suicidal ideation:		Relationship to care recipient:	
Yes	6**	Spouse or parent	16
No	94	Family	35
		Friend	36
		Other	13
Consumption of medications:		Number of types of assistance:	
Yes	19	2 or fewer	28
No	82	3 or 4	37
		5 to 7	35
<i>Subjective mental health*:</i>		Principal caregiver:	
<i>Poor</i>	8**	Yes	33
<i>Adequate</i>	92	No	67
<i>Mental disorders*:</i>		<i>Lives with care recipient*:</i>	
<i>Present</i>	20	Yes	18
<i>Absent</i>	80	No	82
<i>Service use for mental health reasons*:</i>			
Yes	52		
No	48		

* The variables in italics were not included in the final model.

** Coefficient of variation between 15% and 25%; to be interpreted with care.

caregiver was generally a friend (36%) or family member (35%) of the person receiving care. Caregivers' mean age was 41.3 years (± 15). Care recipients suffered mostly from depressive disorders (37%) and substance abuse problems (21%). The mean age of care recipients was 39.0 years (± 16).

Scores for the Caregiving Experience Scale

The average scores for the subscales and their items are presented in Table 3. The higher the score, the more the person reported the particular aspect of the caregiving experience involved. The maximum possible score is 5.

The results by subscales and items show that subscales 1 and 2 have the highest scores (2.8), revealing that caregivers were more often sensitive to care recipients' *Difficult behaviours* (especially *Moody* and *Unpredictable*) and *Negative symptoms* (especially *Withdrawn*). The scores for subscales 3, *Stigma* (1.9), and 4, *Problems with services* (1.8), imply that caregivers were less frequently affected by these aspects. With regard to *Effects on family* (subscale 5); caregivers were aware that care recipients were having difficulty with family relationships, but were not afraid the family would break up. In relation to *Need to back up* (subscale 6); caregivers were more often concerned with providing financial support to care recipients when the need arose, but less often worried about future consequences for their personal finances. In relation to *Loss* (subscale 7); caregivers were more often sensitive to the idea that a loved one might have missed several opportunities during his or her life because of a mental health problem. Finally, subscale 8 (*Good aspects of relationship*) presented a high mean score (2.8), which proves that caregivers often had positive experiences when providing care. In fact, the highest mean scores were among items of this subscale. Finally, a strong positive correlation was observed between the positive subscale and the combined negative subscales ($r = 0.43$), which

TABLE 3
Average Score for Each of the Subscales on the Caregiving Experience Scale
and Their Components, and Cronbach α Values for Anglophones
and Francophones (Weighted Data; $N = 405$)

#	Wording of the Question*	Mean \pm s.d.	Cronbach α	
			franc.	angl.
	During the last 4 weeks, did you think about . . . (1 = <i>never</i> ; 2 = <i>rarely</i> ; 3 = <i>sometimes</i> ; 4 = <i>often</i> ; 5 = <i>nearly always</i>)			
	Subscale 1: Difficult Behaviours	2.8 \pm 0.9	0.86	0.87
Q5a	Moody	3.3 \pm 1.1		
Q5b	Unpredictable	3.1 \pm 1.2		
Q5i	Irritable	2.9 \pm 1.2		
Q5j	Inconsiderate	2.3 \pm 1.2		
Q5k	Behaving in a reckless way	2.5 \pm 1.3		
Q5l	Suspicious	2.6 \pm 1.3		
Q5n	Behaving in a strange way	2.6 \pm 1.2		
	Subscale 2: Negative Symptoms	2.8 \pm 1.0	0.81	0.85
Q5c	Withdrawn	3.0 \pm 1.2		
Q5d	Uncommunicative	2.7 \pm 1.2		
Q5e	Not interested	2.8 \pm 1.2		
Q5f	Slow at doing things	2.8 \pm 1.3		
	Subscale 3: Stigma	1.9 \pm 0.8	0.67	0.65
Q2a	Covering up his/her mental health problem	1.8 \pm 1.1		
Q2b	Feeling unable to tell anyone about his/her mental health problem	2.0 \pm 1.1		
Q3h	Feeling unable to have visitors at home	1.6 \pm 1.0		
Q4c	How to explain his/her mental health problem to others	2.2 \pm 1.1		
	Subscale 4: Problems with Services	1.8 \pm 0.7	0.83	0.82
Q3a	Dealing with psychiatrists	1.6 \pm 1.0		
Q3g	Dealing with mental health professionals	2.0 \pm 1.1		
Q4a	Health professionals not understanding your situation	1.8 \pm 1.1		
Q4f	Making complaints about his/her care	1.4 \pm 0.9		
Q4j	Finding out how hospitals or mental health services work	2.0 \pm 1.2		
Q4k	Doctor's knowledge of services available	1.9 \pm 1.1		
Q4l	Difficulty getting information about his/her mental health problem	2.0 \pm 1.1		

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	Subscale 5: Effects on Family	2.4 ± 0.9	0.79	0.75
Q6j	How he/she gets on with other family members	2.8 ± 1.2		
Q6k	How family members do not understand the mental health problem	2.5 ± 1.3		
Q7a	Effects of the mental health problem on children in the family	2.2 ± 1.4		
Q7b	Mental health problem causing family breakup	2.0 ± 1.3		
Q7d	How the mental health problem affects special family events	2.3 ± 1.3		
	Subscale 6: Need to Back Up	2.2 ± 1.0	0.78	0.77
Q2c	Having to support him/her	2.2 ± 1.3		
Q2j	The effect on your finances	1.9 ± 1.3		
Q3i	Backing him/her up when he/she runs out of money	2.3 ± 1.3		
Q6a	His/her difficulty looking after money	2.2 ± 1.4		
	Subscale 7: Loss	2.2 ± 0.9	0.79	0.68
Q6c	His/her risk of committing suicide	2.2 ± 1.2		
Q6h	Thinks a lot about death	2.1 ± 1.2		
Q6i	His/her lost opportunities	2.7 ± 1.2		
Q6l	How he/she attempts to harm him/herself	2.0 ± 1.2		
	Combined Negative Subscales	2.3 ± 0.6	0.92	0.91
	Subscale 8 (+): Positive Personal Experiences	2.8 ± 0.8	0.84	0.88
Q2d	I have learned more about myself	3.0 ± 1.1		
Q2e	I have contributed to others' understanding of the mental health problem	2.8 ± 1.2		
Q3d	I have become more confident dealing with others	2.3 ± 1.2		
Q3f	I have become more understanding of others with problems	3.4 ± 1.1		
Q3j	I have become closer to some of my family	2.3 ± 1.3		
Q3k	I have become closer to friends	2.4 ± 1.2		
Q3l	I share some of his/her interests	2.8 ± 1.1		
Q3m	I feel useful in my relationship with him/her	3.4 ± 1.0		
Q4g	I have met helpful people	2.4 ± 1.1		
Q4h	I have discovered strengths in myself	3.0 ± 1.2		

* More specifically, for subscales 1 and 2, the wording of the question was: "During the last 4 weeks, did you think the person you are helping was . . ." For the other factors, the question was: "During the last 4 weeks, did you think about . . ."

shows that caregivers who experienced a greater number of negative aspects in caregiving also experienced positive aspects more often.

Predictors of the Caregiving Experience

Table 4 presents the standardized regression coefficients of the final model, once all variables have been introduced. The variation observed in terms of the explained variance percentage (ΔR^2) is also indicated when a new block of variables is added.

Combined negative subscales. Variables included in the *Sociodemographic characteristics of the caregiver* were not determining in relation to the caregiving experience. However, when taken as a whole, they explained 9.6% of the total variance. Variables describing the caregiver's state of mental health, expressed in suicidal ideation and the consumption of medications for reasons of mental health, were also not determining in the evaluation of the caregiving experience. In fact, they only contributed marginally to the explained variance (2.5%).

Characteristics of the care recipient were predictors of the combined negative subscales. Thus, the number of disabilities the care recipient had experienced, the duration of the problem, and whether or not he or she refused assistance were markedly linked to the caregiving experience. The more serious the care recipient's problem, the more significant were the negative aspects of the caregiving experience. Moreover, introduction of these variables into the model improved the explained variance percentage considerably ($\Delta R^2 = 25.1\%$). In relation to the *Caregiving context*, a caregiver's experiences were more negative when the caregiver was a parent of the person receiving care and when he or she provided many different kinds of assistance. These variables raised the explained variance percentage by 13.1%.

These variables accounted for 50.3% of the overall variance of the negative subscale, which is considerable for this type of study.

Distinctiveness of the various negative subscales. The negative subscales differed from one another as regards their predictors. First, similar to the combined negative subscale, the variables in the block *Sociodemographic characteristics of the caregiver* were not determining in relation to the various negative factors of the scale. The variables of the *Caregiver's mental health* block, although they contributed only marginally to the explained variance percentage, nonetheless showed selective associations with some negative subscales. Thus, suicidal ideation was associated with subscales 3 and 7.

Although the *Characteristics of the care recipient* were predictors of the negative subscales, certain distinctive features emerged from the results. The variable *Number of disabilities* was associated with subscales 1, 2, 5, and 7 and the variable *Duration of the problem* was associated with subscales 5, 6, and 7. Therefore, if the care recipient's problem was more serious or had lasted more than 20 years, the impact on family relationships was deemed more significant, and the caregiver could be increasingly affected by losses incurred by the person struggling with a mental health problem. It is also easy to imagine that the longer the problem lasted, the greater the care recipient's need for financial support. Moreover, the number of disabilities the care recipient had experienced and type of services received were predictors of subscales 1 and 2, relative to the care recipient's behaviours. When the care recipient had experienced a number of disabilities or received various types of services or no services at all, the caregiver was more sensitive to the care recipient's difficult behaviours or withdrawal.

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Finally, variables of the *Caregiving context* were major predictors for all the negative subscales and there was little difference from one subscale to another. These variables were particularly determining for subscale 6. The financial needs of care recipients were of greater concern to caregivers who were closer to the people receiving assistance and who provided considerable support. These variables contributed much less to the total variance of subscale 5.

Positive subscale. *Spirituality* is a variable constructed from the response to a question asking respondents to indicate the importance they attribute to spirituality. It is the only variable from the *Sociodemographic characteristics of the caregiver* block that was significantly connected with the positive subscale. The explained variance percentage for this block was 7.1%. Moreover, the caregiver's state of mental health was not linked with a positive caregiving experience once the effect of the caregiver's sociodemographic variables were controlled.

The *Characteristics of the care recipient* were not very determining of the positive aspects of the caregiving experience, in contrast to the negative subscales. The contribution of these variables to the model was only minor ($\Delta R^2 = 4.8\%$), once the effect of the first two blocks of variables was controlled.

However, the *Caregiving context* variables noticeably improved the explained variance percentage ($\Delta R^2 = 13.9\%$). These variables, particularly the number of types of assistance provided by the caregiver and relationship with the care recipient, were strongly linked to the positive subscale. Thus, a caregiver who was very involved in providing assistance felt more enriched; a caregiver who was a friend of the person receiving care also seemed to have more positive personal experiences than a caregiver who was a family member.

All the variables contributed 25.9% to the total explained variance of the positive subscale, which is weak compared to the negative subscales. As Szmukler et al. (1996) acknowledged, it is more difficult to explain or predict what is associated with the positive aspects of caregiving.

DISCUSSION

In our analyses of the caregiving experience, we note first that subscales describing care recipients' behaviours have the highest mean scores. One might conclude from these findings that the caregiver may have difficulty knowing and understanding what the care recipient is going through; therefore, the caregiver may find it difficult to provide assistance. However, subscales related to problems with services and stigma post the lowest scores. This outcome is most likely linked to the composition of the population studied, that is, caregivers of people with all types of mental health problems and not only those with severe and persistent illnesses. These people probably require fewer specialized services and, consequently, caregivers are less connected to the health care system. This situation may also explain why caregivers experience fewer negative effects of the stigma associated with mental illness. However, the complex feelings associated with this stigma may not be expressed to a great degree if they do exist.

The score for the positive subscale is also high. The feeling of being useful or of fulfilling oneself through caregiving emerges in several studies on natural caregivers (Cohen, Colantonio, & Vernich, 2002; Schwartz & Gidron, 2002; Veltman, Cameron, & Stewart, 2002). The caregiving experience can be a source of accomplishment for the caregiver.

TABLE 4
Standardized Regression Coefficients and R^2 for Multiple Linear Regression Analysis*
of Each Subscale on the Caregiving Experience Scale
($N = 405$)

Variable (Reference Category)	F1 Difficult Behav- iours	F2 Neg- ative Sym- ptoms	F3 Stigma	F4 Prob- lems with Ser- vices	F5 Effects on Family	F6 Need to Back Up	F7 Loss	Combined Negative Subscales	F8 Positive Person- al Experi- ences
Sociodemographic Characteristics of the Caregiver									
Sex (Female = 1, Male = 0)	-	-	-	-	-	-	0.10 *	0.09 *	-
Marital status (vs Single)									
Married/common law	-	-	-	0.13 *	-	-	-	-	-
Separated/divorced	-	-	-	-	-	-	-	-	-
Widowed	-	0.13 *	-	-	-	-	-	-	-
Perceived financial status (vs Sufficient)									
Comfortable	-	-	-	-	-	-	-	-	-
Poor/very poor	-	-	-	-	-	-	-	-	-
Place of birth (Elsewhere = 1, Canada = 0)	-	-	0.11 *	0.11 *	-	0.13 *	-	0.08 *	-
Spirituality (Important = 1, Not important = 0)	-	-	-	0.14 *	-	-	-	-	0.15 *
R^2 (%)	6.6	6.7	3.8	7.7	8.2	8.1	4.4	9.6	7.1
R^2 adjusted (%)	4.6	4.6	1.7	5.7	6.1	6.1	2.3	7.6	5.1
F change	3.3 ^b	3.3 ^b	1.8	3.8 ^c	4.0 ^c	4.0 ^c	2.1 ^a	4.8 ^c	3.5 ^b
Mental Health of the Caregiver									
Suicidal ideation (Yes = 1, No = 0)	-	-	0.15 *	-	-	-	0.17 *	0.09 *	-
Consumption of medications (Yes = 1, No = 0)	-	0.13 *	0.11 *	0.12 *	-	0.09 *	-	0.11 *	-
ΔR^2 (%)	0.3	1.9	4.2	1.1	0.9	0.9	3.3	2.5	0.1
ΔR^2 adjusted (%)	-0.2	1.5	3.8	0.6	0.4	0.4	2.9	2.0	-0.4
F change	0.6	3.8 ^a	8.4 ^c	2.2	1.8	1.8	6.5 ^b	5.2 ^b	0.1

A dash indicates that although the variable is included in the model, it is not significant ($p > 0.05$)
^a $p < 0.05$; ^b $p < 0.01$; ^c $p < 0.001$.
^{*} Linear regression by block, using the enter method.

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TABLE 4 (CONT'D)

Variable (Reference Category)	F1 Difficult Behav- iours	F2 Negat- ive Symp- toms	F3 Stigma	F4 Prob- lems with Ser- vices	F5 Effects on Family	F6 Need to Back Up	F7 Loss	Combined Negative Subscales	F8 Positive Person- al Experi- ences
Characteristics of the Care Recipient									
Number of disabilities	0.29 *	0.24 *	-	0.13 *	0.34 *	-	0.26 *	0.30 *	-
Duration of the disorder (vs Less than 1 year)									
1-4.9 years	-	-	-	-	-	-	-	-	-
5-9.9 years	-	-	-	-	-	0.28 *	0.20 *	-	-
10-19.9 years	-	-	-	-	-	0.20 *	0.18 *	0.14 *	-
20 years and over	-	-	-	-	0.20 *	0.27 *	0.21 *	0.19 *	-
Does not know	-	-	-	-	-	0.24 *	-	-	-
Responsiveness to care (Accepts = 1, Refuses = 0)	-0.16 *	-	-0.18 *	-	-	-0.13 *	-0.10 *	-0.17 *	-
Type of services received (vs Professional services only)									
Intensive services	0.15 *	0.11 *	-	-	-	-	-	-	-
No services	0.14 *	0.15 *	-	-	-	-	-	0.09 *	-
ΔR^2 (%)	20.6	15.1	7.4	10.4	17.3	11.9	15.5	25.1	4.8
ΔR^2 adjusted (%)	19.3	13.5	5.4	8.6	15.9	10.2	13.9	24.2	2.6
F change	11.2 ^c	7.8 ^c	3.5 ^c	5.1 ^c	9.1 ^c	6.0 ^c	8.0 ^c	15.7 ^c	2.2 ^b
Caregiving Context									
Relationship to the care recipient (vs Other)									
Spouse	-	-	-	-	-	0.14 *	-	-	-
Parent	0.14 *	-	-	0.20 *	-	0.21 *	-	0.20 *	-
Close family	0.14 *	-	0.15 *	-	0.16 *	-	-	0.13 *	0.19 *
Extended family	-	-	-	0.15 *	-	-	-	-	0.15 *
Friend	-	-	-	-	-	-	-	-	0.25 *
Principal caregiver (Yes = 1, No = 0)	-	-	0.14 *	-	-	0.13 *	0.14 *	0.13 *	-
Number of types of assistance	0.12 *	0.20 *	0.16 *	0.29 *	-	0.35 *	0.13 *	0.26 *	0.28 *
ΔR^2 (%)	5.8	6.5	7.8	11.7	3.4	18.6	5.4	13.1	13.9
ΔR^2 adjusted (%)	4.6	5.4	6.6	10.8	2.1	18.4	4.2	12.8	12.8
F change	4.3 ^c	4.6 ^c	5.1 ^c	8.4 ^c	2.4 ^a	15.4 ^c	3.8 ^b	13.1 ^c	7.0 ^d
Total R^2 (%)	33.3	30.2	23.2	30.9	29.8	39.6	28.7	50.3	25.9
Total R^2 adjusted (%)	28.3	25.0	17.5	25.7	24.5	35.1	23.3	46.6	20.1

A dash indicates that although the variable is included in the model, it is not significant ($p > 0.05$);
^a $p < 0.05$; ^b $p < 0.01$; ^c $p < 0.001$.

As for the predictors of the caregiving experience, regardless of subscale, our model explains a large part of the total variance: 50.3% for the combined negative subscales. We also note that the *Characteristics of the care recipient* and *Context of caregiving* are the most significant contributors.

More specifically, as regards sociodemographic characteristics, no determining link stands out. However, the caregiver's sex seems to be connected to the caregiving experience, with women reporting more concerns. Other studies also note that women tend to experience more stress related to their roles as caregivers (Yee & Schulz, 2000). It is also important to take into consideration the association with place of birth, even though it is not determining, since people born outside Canada are probably less familiar with the health care system and may be more likely to face a language barrier. Moreover, the Montreal Mental Health Survey (Fournier, Lemoine, Poulin, & Poirier, 2002) showed that people whose mother tongue is neither French nor English seem to have more negative beliefs about mental illness and have less knowledge about mental disorders and the health care needs that arise. This is an essential factor to consider in enhancing cultural appropriateness of services for caregivers.

By and large, the *Mental health of the caregiver* block did not contribute significantly to the model, especially to the positive subscale. Initially, this weak association can seem surprising since several studies using the ECI have shown that this scale is a good predictor of caregivers' distress or well-being (Harvey et al., 2001; Joyce et al., 2000; Martens & Addington, 2001; Szmukler et al., 1996). However, certain nuances are necessary. First, the population we studied differed greatly from that in other studies, if only because ours was composed of principal and secondary caregivers of friends or relatives with a variety of emotional or nervous disorders. Also, it is necessary to be cautious when associating a high level of psychological distress with the presence of a recognized mental health disorder. The definition of mental health goes beyond an absence of symptoms linked to depression, anxiety, or other mental disorder (Poulin, Lemoine, Poirier, & Lambert, in press). Nevertheless, a high level of distress is strongly associated with mental disorders, and the tools used to measure psychological distress are powerful instruments of prediction of strain on services. Research has shown that a high level of psychological distress is associated with consulting health professionals, an increase in alcohol and psychoactive substance consumption, a negative self-evaluation measure assessing state of mental health (Massé, Poulin, & Battaglini, 1998; Massé, Poulin, Dassa, et al., 1998), and suicidal ideation (Boyer et al., 2000). Since caregivers' psychological distress was not measured in the survey,¹ we were unable to study its specific association with the scale. Nonetheless, it is interesting to note that the only variables describing caregivers' state of mental health that are associated with the scale are the presence of suicidal ideation and consumption of medications for mental health reasons, both of which are linked to psychological distress.

The characteristics of the care recipient, which qualify the severity of his or her problem, are major predictors of the caregiver's experience, especially its negative aspects. Type of disorder does not seem to play such a role. Our results match those of other studies which have clearly established that it is the severity of a person's symptoms and his or her social functioning, and not the nature of the diagnosis, that are linked to the caregiver's subjective burden and distress (Baronet, 1999; Biegel, Milligan, Putnam, & Song, 1994; Harvey, 2000; Joyce et al., 2000; Szmukler et al., 1996). A caregiver's more negative appraisal of the caregiving experience is mostly associated with the inability of the care recipient to perform his or her regular activities (Szmukler et al., 1996).

Other determining variables in the caregiving experience are those that describe the caregiving context from the vantage point of the caregiver's commitment. These results corresponded to those of Harvey (2000), who recognized that commitment to

caregiving is a central element in both negative and positive appraisals of the caregiving experience. These variables are particularly important in determining the positive aspects. Caregivers who are very committed to providing assistance find it particularly rewarding. The significance of the positive aspects of caregiving is increasingly recognized (Cohen et al., 2002; Schwartz & Gidron, 2002; Veltman et al., 2002).

Moreover, the strong correlation observed between the positive and negative aspects of the subscales shows that the caregiving experience is not unipolar, that is, either negative or positive. On the contrary, it can be difficult and rewarding or burdensome and gratifying. These results are consistent with those of other studies (Harvey, 2000; Nijboer, Triemstra, Tempelaar, Sanderman, & Van Den Bos, 1999).

The cross-sectional nature of the survey significantly limits the study, since causal relationships between the components studied cannot be established. Thus, the relationship between the negative dimensions of the caregiving experience, the state of the caregiver's mental health, and psychological distress should be investigated more thoroughly. In addition, it would have been interesting to consider the importance of the emotional connection between the caregiver and the care recipient among the predictors of the caregiving experience. Emotional commitment was mentioned indirectly only through the number of types of assistance provided and the formal link with the care recipient (parent, spouse, etc.). Emotional attachment can result in the caregiver feeling more concern for the care recipient's problem, as well as finding caregiving more satisfying and rewarding.

This study demonstrates that the caregiving experience is linked to the caregiver's commitment. Providing care to a care recipient demands a constant re-evaluation of the caregiver's commitment to the recipient and constant reassessment of the arrangements made to balance caregiving, paid work, and family and personal life. The difficulty in reconciling commitment and detachment in the caregiving relationship is a major concern for the caregiver. Measures that aim to facilitate the caregiver's task should seek to strike a balance that enables the caregiver to consider his or her own needs as well. However, this approach, suggested by Harvey (2000), is possible only when alternative solutions exist, which is not always the case.

Moreover, it would be interesting to explore more thoroughly the factors that foster positive aspects of the caregiving relationship, and the evolution of the negative and positive aspects of this relationship over time. Do the caregiver's fatigue and concerns become more apparent, and supersede feelings of usefulness and achievement? Or is it that the caregiver is worn out and the chronic nature of the problem leads to loss of hope that the situation will improve? These are some of the issues that could be examined more closely.

NOTE

1. We had planned on including a measure of psychological distress in the telephone survey. However, because of the duration of the telephone interview and the difficulty of administering the psychological distress scale over the telephone, we had to remove this measure from the interview after the pre-test. Consequently, it was no longer possible for us to include it in the self-administered questionnaire.

RÉSUMÉ

Fournir de l'aide à un(e) proche souffrant de problèmes de santé mentale n'est pas sans répercussions sur la santé physique ou mentale de l'aidant ou l'aidante. Dans le cadre de l'Enquête sur la santé mentale des Montréalais, 405 aidants et aidantes de proches aux prises avec de tels problèmes ont participé à un volet postal portant sur leur expérience d'aide. Le but de cet article est de décrire et évaluer cette expérience et de cerner ses déterminants. Les résultats montrent que la gravité du problème de l'aidé ou l'aidée est surtout déterminante pour les aspects négatifs de l'expérience d'aide alors que le contexte de l'aide l'est pour les aspects positifs et négatifs de l'échelle. Une forte corrélation est observée entre les dimensions positives et négatives de l'échelle, montrant que l'expérience d'aide n'est pas unipolaire mais, qu'au contraire, elle peut être à la fois lourde et gratifiante.

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