

Correlates of Well-Being Among Caregivers of Cognitively Impaired Relatives

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Les caractéristiques et l'utilisation des services de relève de soixante-quatre soignants s'occupant de clients qui ont de graves troubles d'apprentissage ont été mises en corrélation avec le pointage des objectifs de vie et celui des conséquences de ce fardeau pour les soignants. Le bien-être des soignants était identique pour les utilisateurs de divers services de relève. Les corrélats du bien-être des soignants, malgré leur fardeau, étaient la vigueur et la perception positive qu'ils avaient ou non de la maladie. L'objectif de vie du soignant a été modifié par sa perception de la reconnaissance sociale de son activité, mais l'influence des deux variables cognitives était prépondérante.

The characteristics and use of respite services of 64 caregivers of severely cognitively impaired clients were correlated with the caregivers' purposes-in-life and burden outcome scores. Caregiver well-being was similar across users of a variety of respite service packages. Correlates of caregiver well-being, in spite of their burdens, were caregiver hardiness and favourable meaning given illness. Both of these cognitive variables exceeded the importance of perceived social support in explaining the variation in caregiver purpose-in-life.

The prevalence of cognitive impairment among seniors living in the community ranges between 4.2% and 6.7% (Cetinski, 1991; Chambers, 1991; Ellis, 1991; Jorm, Korten, & Henderson, 1987). These figures increase with age, and in every country the rate of growth in cognitive impairment outstrips the growth of the population (Jorm, 1990). Family members are now important caregivers for impaired older adults. Family caregiving is often stressful and the level of well-being among caregivers is not well documented (Biegel, Sales, & Schultz, 1991). There is a need to identify high-risk caregivers who could benefit from interventions designed to increase their well-being, and to evaluate the interventions themselves.

Thus, the objective of this study was to describe the characteristics of individuals who care for cognitively impaired relatives in their homes, and to determine variables associated with their well-being, including their choice of

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a range of community services. More specifically, the current study addressed two questions: firstly, among the caregiving relatives of cognitively impaired adults, what characteristics distinguish those who make use of the Seniors' Day Program from those who use other services? Secondly, what variables correlate with the variability in caregivers' purpose-in-life in spite of their relatives' severe cognitive impairment?

Literature Review

Chronically ill and disabled elders are cared for primarily by their families (Chambers, 1991), with some members finding caregiving to be burdensome and stressful and others deriving a sense of satisfaction. Previous studies on the correlates of caregiver burden and depression have multiple methodologies, small and non-representative sample sizes (e.g., Biegel et al., 1991 used samples from hospitals), and single outcome measures of, usually, negative mood states. Most examined only the negative features of caring – its burden, distress, and associated depression (Mohide et al., 1990; Neundorfer, 1991), and failed to acknowledge the existence of divergent and competing views about this stressful situation. Without an adequate knowledge of both the correlates of burden and well-being, and a full understanding of the different contexts of additional services used by caregivers, neither the nature nor the level of service strategies can be designed or targeted (Montgomery, Gonyea, & Hooyman, 1985). Studies are needed to assess the burden as well as the well-being of carers.

Nevertheless, some generalizations can be made from these studies. The relative's level of disability, severity of dementia (in husbands), and duration and characteristics of the illness are not related to caregiver depression or burden (Boss, Caron, Horbal, & Mortimer, 1990; Gwyther & George, 1986; Zarit, Reeves, & Bach-Peterson, 1980; Zarit, Todd, & Zarit, 1986) with one exception. Fitting, Robins, Lucas, and Eastham, (1986) identified some gender differences in caregiver tolerance, with women reporting more depressive symptoms than men. This gender difference was not supported by findings from other longitudinal studies (Zarit et al., 1986). Further, the amount of day care received and number of other services used appeared to have only a small impact on caregiver distress (Lawton, Brody, & Saperstein, 1989; Wells, Jorm, Jordan, & LeFroy, 1990). This finding was attributed to the small amount of relief in light of the degree of stress, and the possibility that caregivers wait too long before obtaining help (Wells et al., 1990).

The ability of caregivers to tolerate problem behaviours is quite variable and can change from day to day. Caregiver tolerance is related to the favourable meaning or positive attributions given the problem behaviours (Boss et al., 1990), and increases with time (Zarit et al., 1986). It appears that

the caregivers' perception of the situation (Boss et al., 1990; Hayley, Levine, Brown, Bartolucci, 1987; Zarit et al., 1980), that is, its negative meaning and appraised stressfulness, is attenuated by caregivers' perceived social support (Boss et al., 1990; Gilleard, 1985; Gilleard, Gilleard, & Whittick, 1984; Hayley et al., 1987; Montgomery et al., 1985; Wells et al., 1990; Zarit et al., 1986). This appraised stressfulness and supportiveness coupled with the caregivers' sense of freedom (Montgomery et al., 1985), mastery (Boss et al., 1990), control (Hayley et al., 1987), and other forms of meaning given illness (Browne et al., 1988) are more fruitful avenues of research (Hayley et al., 1987) in explaining caregiver well-being (purpose-in-life) in the face of distress and/or burden.

A community sample of referrals to a day program was thought to be representative of all caregivers. In addition, measures of the well-being of carers could then be compared to those of other individuals in the population, and thereby provide an estimate of the relative burden imposed by caring.

The positive response to the stress of caring for a cognitively impaired relative has rarely been addressed even in recent studies (Neundorfer, 1991) or critical reviews (Kuhlman, Wilson, Hutchinson, & Wallhagen, 1991). Caregivers with better adaptational skills and life satisfaction or well-being outcomes were those who had better problem-solving and coping strategies, higher perceived adequacy of social supports (Hayley et al., 1987), and used day programs (George & Gwyther, 1986). There is some preliminary evidence about caregiver well-being, hardiness, and purpose in the face of the burden which accompanies caring for a cognitively impaired relative. The multidimensional nature of caregivers' appraisal of their situation is rarely captured. The current study distinguishes burden from well-being, an important oversight of previous studies (Biegel et al., 1991).

Conceptual Framework

Based on Lazarus and Folkman's (1984) theory of stress and coping, it was postulated that the meaning given the illness would be related to purpose and correlated with a caregiver's resilience (hardiness) and perceived social support. These perceptions play a role in promoting well-being even when chronic stress is apparent. Thus, it was hypothesized that these variables would explain a large proportion of the variability in caregivers' purpose in life.

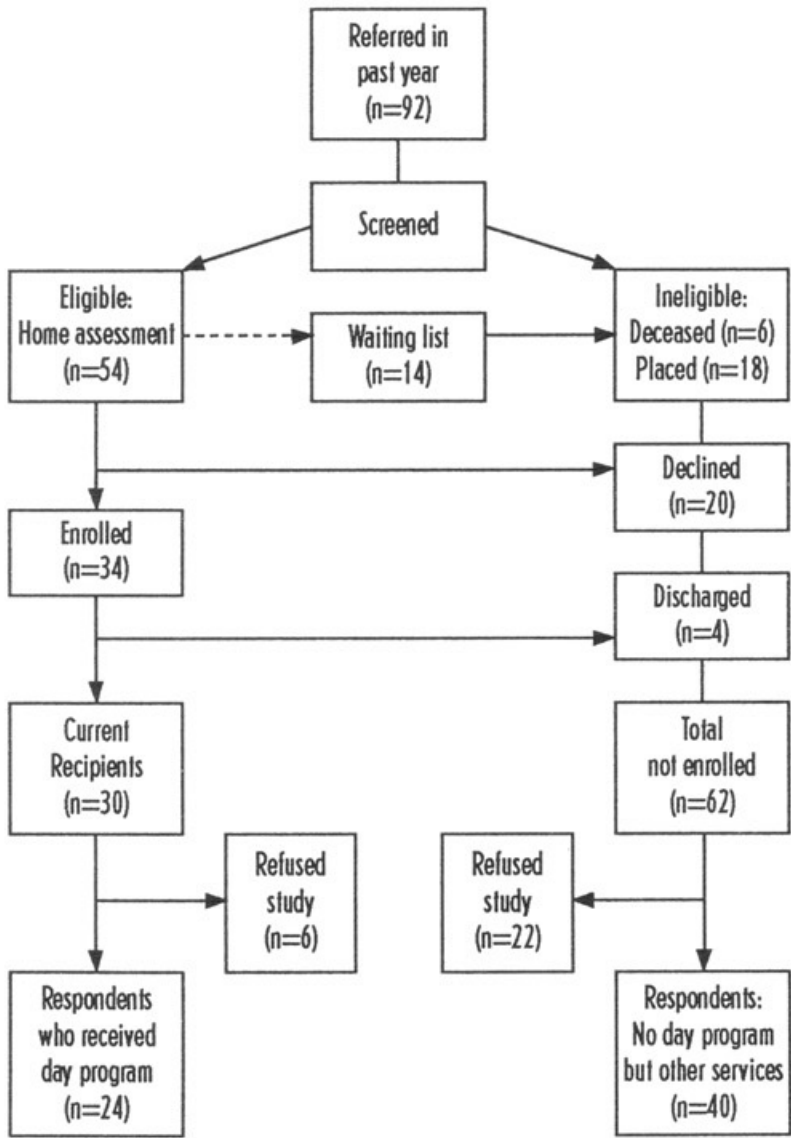
Method

A Seniors' Day Program for mobile elderly individuals who had moderate to severe cognitive impairment, served as the site of investigation. Cognitively impaired seniors attended the program for a half day or full day weekly. Over the preceding three years 60 to 75% of eligible participants had enrolled

in the program. At the time of the current study (June, 1991) four new participants were being admitted per month from a waiting list of 14 participants after waiting approximately six weeks from the time of referral.

All caregivers of eligible participants referred to the Seniors' Day Program in the preceding year ($N=92$) received a letter announcing the study (Figure 1).

Figure 1
Study flow diagram, April 1990–1991



Caregivers were phoned by the research assistant and asked for their consent to participate in this study. Approximately 80% of caregivers with relatives enrolled in the program and 66% of those whose relative were not enrolled participated in the study. Study participants included caregivers with relatives who were currently enrolled ($N=24$), no longer enrolled and in an institution ($N=18$), on the waiting list ($N=14$), or had declined enrollment ($N=8$) (Table 1). Home visits were arranged to obtain caregivers' consent and to administer questionnaires in a semi-structured format.

A historic cohort analytic study design was used (Hennekens & Buring, 1987), where exposure to the program or not preceded the outcome assessment, as in Figure 1. Here the characteristics and outcomes of those who received the day program can be compared to those who did not (i.e., waiting, declined, or no longer participating).

Measurements

The main outcome variable was purpose-in-life. Other measures included positive and negative beliefs and attitudes (explanatory variables) which were thought to influence the caregiver's purpose-in-life.

The Purpose-in-life questionnaire is a 20-item, seven-point scale (1 to 7) designed by Crumbaugh & Maholick (1969, 1981) that measures the degree to which a caregiver experiences a sense of meaning or purpose-in-life. A sample question includes the choices "In thinking of my life I often wonder why I exist" versus "I always see a reason for being here." The split-half correlation coefficient was .85 to .92. Test-retest ranges were between .68 and .83 (Crumbaugh & Maholick, 1969, 1981) and construct validity was assessed on seniors by its relationship to a recent measure of the meaning in life ($r=.77$) and affect balance scale ($r=.63$) (Warner & Williams, 1987). The score ranges between 20 and 140. Scores less than 92 indicate lack of a clear purpose; between 92 and 111 indicate indecisiveness; and greater than 111 indicate definite purpose and meaning in life (Crumbaugh & Maholick, 1981).

The Caregiver Burden interview is a 22-item, 5-point scale (0 to 4) designed to evaluate the subjective impact of caregiving (Zarit et al., 1986). A sample question is "Do you feel (_____) asks for more help than s/he needs?" The internal consistency was estimated as .88 using Chronbach's alpha. Test-retest reliability was .71. Validity was assessed by correlating the total score with a single burden item ($r=.71$) and with the Derogatis (1982) Brief Symptom Inventory (BSI), ($r=.41$) (Butt, 1989).

The "direct service" component of the Browne, Arpin, Corey, Fitch, Gafni (1990) Health and Social Service Utilization Inventory was used to

assess the caregivers' Use of Services for their cognitively impaired relatives. Caregivers in all user groups were asked to list the number and type of community services they had received in the preceding year (e.g., Visiting Nursing, Day Program, Meals-On-Wheels, Friendly Visitors, Red Cross Homemakers).

The Meaning-Given-Illness Questionnaire is a second-generation, 23-item, seven-point measure (on a scale of 0 to 6) of meaning given illness. It was designed to quantify the degree to which individuals apply a mix of primary appraisals to illness: the number, type, seriousness, stability, desirability, expectancy, controllability, and uncertainty (Browne et al., 1988; Lazarus & Folkman, 1984). Test-retest reliability was .60 to .77. Validity was assessed by its ability to distinguish the adjustment patterns of persons with chronic illness. Sixty percent of the variance in poor adjustment to chronic illness can be explained by unfavourable meaning given the illness (Browne, Byrne, Roberts, et. al, 1988). The questionnaire was broken down into five independent types of meaning given illness where the higher the score, the more favourable the meaning: level of adverse impact, harm/disability, stress, challenge and vulnerability.

Hardiness (Commitment-Control-Challenge) is a 50-item, four-point (scale of 0 to 3) third-generation measure of the caregiver's resilience or hardiness. It consisted of three distinct constructs of commitment: belief in the value or importance of what one is doing (caring); control or tendency to believe one can influence the course of events; and challenge where change is viewed as an opportunity or incentive (Kobasa, Maddi, Kahn, 1982; Kobasa, personal communication, 1990). Control and challenge can be summed up as courage. The extensive reliability and validity of the Hardiness measure have been documented (Orr & Westman, 1990) and it has been widely accepted as a moderator of stress across ages, occupations, and genders.

The Personal Resource Questionnaire (Weinert, 1987), is a second-generation multidimensional, 25-item, seven-point measure (on a scale 1 to 7) of social support, consisting of five dimensions of support: intimacy, social integration, nurturance, worth, and assistance/guidance. It has been tested on older persons, has a test-retest reliability of .72, and distinguishes anxious and depressed populations in predicted directions (Weinert, 1987).

The Reisberg (1984) Stages of Cognitive Decline Scale measured global deterioration. This scale expands the seven-point Global Deterioration Scale (Reisburg, Ferris, DeLeon, & Crook, 1982) and provides descriptors of functional capacity related to activities of daily living. The scale ranges from 1=normal to 7=late dementia, and correlates significantly with 25 of 26 other measures of memory and cognitive decline (Reisburg et al., 1982).

Sociodemographic Variables: Caregivers were described in terms of age, gender, education, culture, residence, income characteristics, and length of time having lived with the cognitively impaired person.

Data Analysis

Caregiver characteristics were described with descriptive statistics in order to compare caregivers of relatives using the day program to others whose relatives were not. They are identified as Enrolled, Refusers, Institutionalized, and Waiting. The four different groups of caregivers were compared using analysis of variance. The order and importance of variables used to predict caregiver well-being was examined through forward stepwise regression. Pearson correlation coefficients were used to determine the relationships of caregiver psychosocial variables to purpose-in-life.

Results

The 64 caregivers in all four groups were, on average, high school graduates approximately 57 to 63 years of age, caring for severely cognitively impaired relatives (5.0 to 5.7 on a 7-point scale) indicating some current difficulty with toileting, dressing, bathing, and eating (Table 1). Caregivers had been caring for these relatives on average for 3 to 5.4 years and perceived their income as "so-so" on a scale from "Poor to Wealthy." Fifty-seven to 78% of caregivers were female and 75 to 79% were living with their relative at home. Fifty to 58% of caregivers were spouses and the remainder were mostly adult children of the impaired relative. In addition to the day program, community dwelling caregivers used, on average one to two other services three times per week. The refusers and Institutionalized groups of caregivers had relatives with more severe cognitive impairment and functional disability ($F_{3,60} = 3.89, p < .01$).

Some of the caregivers lived with their cognitively impaired relative ($N=37$), while others did not ($N=27$). Of the 18 relatives who were in institutions, two were in an acute care hospital awaiting placement and their relatives still considered themselves to be living with them. Caregivers who lived with their relatives were less "hardy" and particularly had less challenge in their lives ($r = -.24$), perceived more burden ($r = .24$), and reported more adverse impact of the illness on their lives ($r = -.38$) than did those who did not live with their relatives. While these relationships are not strongly correlated, it is possible that the study failed to capture, qualitatively, the level of burden that may have been experienced by caregivers recently separated from their relatives as a result of institutional placement.

Table 1

The characteristics of caregivers and their cognitively impaired relatives across service user groups

		Enrolled in day program (N=24)		Waiting for day program (N=14)		Refused day program: In-home service only (N=8)		Institution- alized (N=18)				
		Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	F _{3,60}	P	
RELATIVE	Severity of illness	5.1	(0.8)	5.0	(0.5)	5.5	(0.6)	5.7	(0.4)	3.89	0.01	
	Years/Educ	12.3	(3)	13.4	(3)	12.9	(3)	12.4	(3)	0.50	0.69	
	Age	59.0	(14)	57.0	(17)	61.0	(15)	63.0	(17)	0.41	0.75	
	Duration/Yrs with illness	5.0	(3)	3.1	(2)	5.4	(3)	4.8	(3)	1.56	0.21	
	Perceived income	3.0	(.5)	3.0	(1)	3.0	(4)	3.0	(1)	0.57	0.64	
	Community services used	1.1	(1)	1.5	(1)	1.5	(1)	0.3	(0.7)	5.29	0.003	
	Frequency services used in 2 weeks	6.0	(5.6)	7.4	(6.4)	7.4	(6.0)	0.44	(1.4)	6.70	0.001	
		N	(%)	N	(%)	N	(%)	N	(%)	X ²	DF	P
CAREGIVER	Female sex	17	(71)	8	(57)	6	(75)	14	(78)	1.7	3	0.63
	Living with Spouse	18	(75)	11	(79)	6	(75)	2	(11)	22.5	3	0.0001
	Daughters/ sons	14	(58)	7	(50)	4	(50)	10	(56)	0.32	3	0.95
	Others	7	(29)	5	(36)	3	(38)	4	(22)	0.96	3	0.81
	English- speaking Canadians	3	(13)	2	(14)	1	(12)	4	(22)	0.85	3	0.84
		11	(46)	8	(57)	6	(75)	10	(56)	2.1	3	0.55

The mean scores for hardiness, social support, favourable meaning, perceived burden, and purpose are displayed in Table 2. The higher the score, the greater the perception in the group.

Uniformly, caregivers in all groups revealed that they had high levels of social support and purpose, and moderate levels of hardiness, favourable meaning, and perceived burden. In total there were 13 caregivers (20%) who lacked a clear purpose (score below 92), 28 caregivers (44%) who demonstrated indecisiveness (score 92-112), and 23 caregivers (36%) could be classified as having definite purpose (score ≥ 113). There was no statistically or substantively important difference in caregiver characteristics between user groups on any variable except two of the types of meaning-given-illness.

Table 2

Characteristics of caregivers of cognitively impaired relatives in four service user groups

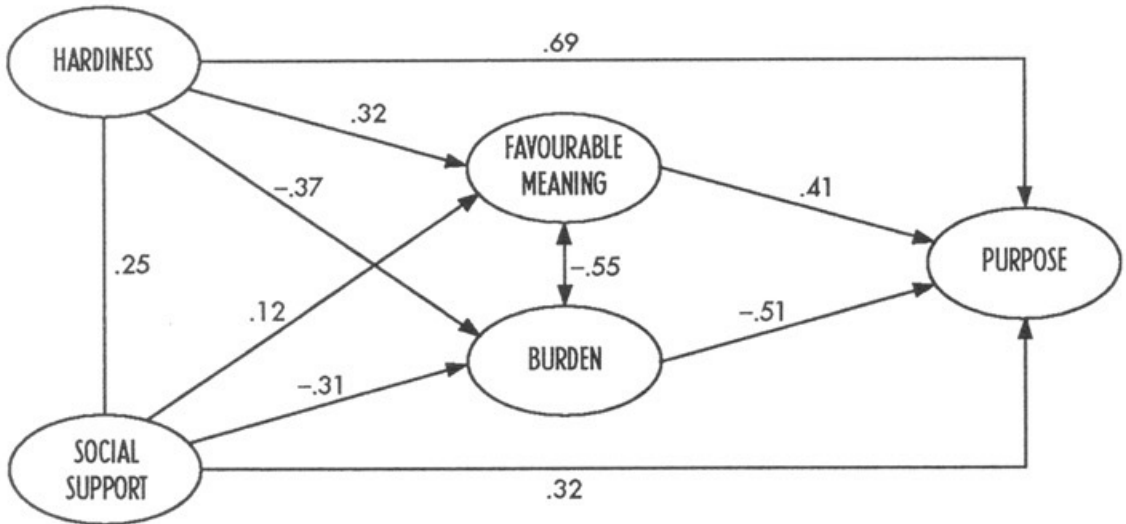
Variables	Score range	Enrolled in day program (N = 24)	Waiting for day program (N = 14)	Refused day program – in-home services only (N = 8)	Institutionalized (N = 18)		
Explanatory	N	\bar{x} (SD)	\bar{x} (SD)	\bar{x} (SD)	\bar{x} (SD)	F _{3,60}	P
Hardiness Total	0–150	69 (1.4)	69 (11)	64 (11)	72 (10)	0.84	0.48
• Challenge		0.54 (0.15)	0.56 (0.15)	0.53 (0.20)	0.57 (0.17)	0.16	0.92
• Commitment		0.76 (0.18)	0.77 (0.11)	0.73 (0.12)	0.82 (0.09)	1.15	0.34
• Control		0.77 (0.16)	0.74 (0.12)	0.67 (0.08)	0.77 (0.12)	1.34	0.27
Social Support Total	25–175	139 (21)	130 (20)	133 (22)	141 (28)	0.78	0.51
• Intimacy		29 (6)	27 (5)	29 (7)	29 (8)	0.35	0.79
• Social integration		26 (6)	25 (7)	23 (9)	28 (6)	0.79	0.50
• Nurturance		28 (5)	29 (4)	27 (4)	29 (5)	0.24	0.86
• Worth		30 (8)	27 (5)	27 (5)	29 (6)	1.30	0.28
• Assistance		27 (8)	23 (7)	27 (5)	28 (8)	1.20	0.39
Favourable meaning given to illness	0–30	15.25 (3.4)	16.1 (2.6)	17.4 (3.0)	17.5 (3.8)	1.90	0.14
• No negative impact	0–6	2.5 (1.3)	2.8 (1.2)	3.1 (0.8)	3.8 (1.9)	2.70	0.05
• Less harm/disability	0–6	1.9 (1.2)	2.7 (1.4)	3.3 (0.8)	2.7 (1.2)	3.40	0.02
• Less stress	0–6	3.2 (1.3)	3.1 (0.9)	3.2 (1.0)	3.6 (1.0)	0.88	0.46
• Challenge	0–6	2.7 (1.0)	3.0 (0.9)	3.1 (1.1)	2.6 (0.7)	0.80	0.50
• Less vulnerability	0–6	4.9 (1.1)	4.4 (1.3)	4.7 (1.2)	4.8 (1.2)	0.55	0.65
Perceived burden	0–4	1.8 (0.66)	1.9 (.54)	1.8 (0.61)	1.4 (0.79)	2.10	0.11
Outcome							
Purpose-in-life	20–140	103 (19)	102 (14)	99 (13)	109 (14)	0.95	0.43

Enrolled and waiting-for-the-day-program caregivers exhibited more unfavourable meaning-given-illness ($F_{3,60} = 2.7$ to 3.4 , $p = .05$ to $< .02$) in terms of adverse impact, harm, and disability, compared to caregivers who refused the day program or whose relatives were institutionalized. This finding, however, could be due to chance which occurs in a situation of multiple testing. The findings of no difference in caregiver status for most variables suggests that the four types of caregivers were able to meet most of their needs through different types of service, and thus able to achieve a similar amount of relief.

Using stepwise regression, hardiness was the most important variable ($r = .69$, $r^2 = .48$, $p < .00001$) explaining the caregiver's purpose-in-life, and meaning of stressfulness of illness ($r^2 = .59$, $p < .0001$) added an additional 11% of the variance. Greater hardiness and less stressful meaning given illness were the important variables that explained the variance in purpose-in-life; together they explained 59% of the variability.

Figure 2

Correlates among variables that explain caregiver wellbeing ($N=64$) when the severity and duration of the illness is held constant



The attributes of the caregiver which correlate with each other in a statistically significant fashion ($p < .05$, 2-Tailed Pearson correlation coefficient of .25 or greater) and well-being or purpose are displayed in Figure 2. There were no relationships between the severity or duration of illness, income or use of health services. In this study of people referred to the day program, the severity and duration of illness was uniformly extreme and can be viewed as controlled for by the study design. Caregiver hardiness (commitment, challenge, control) was somewhat independent of social support ($r = .25$) and these two variables may make a distinct contribution to purpose-in-life. There was a strong correlation between favourable meaning and burden ($r = .55$) but the correlations between burden and purpose was slightly higher.

Discussion

Caregivers of relatives enrolled and waiting for the day program were similar to other caregivers not using the day program in exhibiting moderate to high levels of social support, purpose-in-life, and realistic views of the moderate to high level of burden imposed by caring for their relative. Caregivers of relatives enrolled in the Seniors' Day Program differed from the other groups by giving less favourable meaning to illness. There are several possible explanations for the lack of differences observed between groups. Well-being can be maintained in a variety of additional ways, and one day a week in a day program may provide an insufficient amount of respite for the caregiver to produce significant outcomes compared to other services.

Further, 60% of the caregivers' purpose-in-life could be explained by a general sense of control, commitment, and challenge (hardiness) with a more favourable meaning of less stressfulness of the illness. The goal for those who counsel caregivers should therefore be to increase their sense of control (hardiness) and find commitments and challenges in life in spite of the burden of caring for their relatives. Caregivers should also be helped to re-examine their unfavourable conceptions of illness. A cognitive-behavioural counselling approach would be best suited to the goal of fostering outside interests, favourable cognitions, and coping efforts.

These findings corroborate the theoretical relationships regarding the role that perceptions, attitudes, and meaning given illness play in promoting resilience and well-being in the face of chronic strain (Lazarus & Folkman, 1984). Caregiver well-being was sometimes high in spite of moderate to high levels of burden. Hardiness and favourable meaning given illness were fairly independent of perceived social support in explaining purpose in the face of burden. Practitioners should be encouraged to assess these characteristics of caregivers in order to determine which interventions are appropriate.

Acknowledgements: This research was supported by the Ontario Ministry of Community & Social Services and the Ontario Ministry of Health.

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