

# Hope, health work and quality of life in families of stroke survivors

Anna Bluvol MScN RN

Nurse Clinician, Stroke Rehabilitation Program, St Joseph's Health Care, London, Ontario, Canada

Marilyn Ford-Gilboe PhD RN

Associate Professor, School of Nursing, H37 Health Sciences Addition, University of Western Ontario, London, Ontario, Canada

Submitted for publication 13 September 2002

Accepted for publication 26 November 2003

Correspondence:

Anna Bluvol,

Stroke Rehabilitation Program,

St Joseph's Health Care,

Parkwood Site,

801 Commissioners Road East,

London,

Ontario,

Canada N6K 5J1.

E-mail: [anna.bluvol@sjhc.london.on.ca](mailto:anna.bluvol@sjhc.london.on.ca)

BLUVOL A. & FORD-GILBOE M. (2004) *Journal of Advanced Nursing* 48(4), 322–332

## Hope, health work and quality of life in families of stroke survivors

**Aim.** This paper reports a study to examine the relationships among hope, family health promotion, and quality of life after stroke, by testing hypotheses derived from the Developmental Model of Health and Nursing.

**Background.** Little attention has been given to the influences of family strengths on health promotion behaviours and quality of life after stroke. The majority of studies have focused on stroke survivors, not their spouses.

**Method.** A descriptive, correlational study was carried out with 40 families of stroke survivors with moderate to severe functional impairments and their spouses. Both partners completed the Herth Hope Index (measure of hope), the Health Options Scale (measure of health work), the Reintegration to Normal Living Index (measure of quality of life) and a demographic questionnaire.

**Results.** For both partners, moderate, positive relationships were found between hope and health work ( $r = 0.52$ ,  $r = 0.39$ ,  $P < 0.01$ ) and between hope and quality of life ( $r = 0.59$ ,  $r = 0.32$ ,  $P < 0.05$ ). Family health work was positively associated with quality of life of stroke survivors ( $r = 0.50$ ,  $P \leq 0.001$ ), but not their spouses. Spouses' employment status, number of supports and functional independence at discharge predicted 40.6% and 46.3% of the variance in quality of life for stroke survivors and spouses, respectively, with the combination of hope and health work contributing an additional 17.8% in predicting stroke survivors' quality of life but no additional variance to the prediction of spouses' quality of life.

**Conclusion.** Theoretical relationships of the Developmental Model of Health and Nursing were supported for stroke survivors, but the model was less useful in explaining spouses' experiences of hope, health work and quality of life. Findings provide direction for identifying 'at risk' families and raise awareness of the contribution of caregiver burden to quality of life in families of stroke survivors.

**Keywords:** stroke, hope, quality of life, caregiver burden, health work, Developmental Model of Health and Nursing, health promotion, family

## Background

Stroke is the fourth leading cause of death and a leading cause of long-term disability in Canada (Heart and Stroke Foundation of Ontario 2002). Given the financial and emotional

burden of stroke on individuals, families and society, there is a pressing need to study how families cope with the consequences of stroke and resulting disability. With up to 80% of stroke survivors returning to the community (Anderson *et al.* 1995), the support of family caregivers plays a key role in

determining whether stroke survivors remain outside institutions and are able to return home after rehabilitation.

Disability in an individual affects the entire family system. Thus, families face changes associated with adjusting to the physical, emotional and psychological consequences of stroke, which often constrain their social roles and activities (Clarke *et al.* 1999) and reduce quality of life of both stroke survivors and their spouses (Bugge *et al.* 1999). While the burden of caregiving has been found to affect family members' physical and psychological well-being negatively (Canam & Acorn 1999, King *et al.* 2001), caregivers have also reported satisfaction with their lives and have expressed positive feelings about their roles and ability to problem-solve and cope with the stroke sequelae (Viitanen *et al.* 1988, Astrom *et al.* 1992, King 1996, Lofgren *et al.* 1999, Pilkington 1999, Hackett *et al.* 2000). However, little attention has been given to identifying family strengths that affect quality of life of both stroke survivors and spouses in the aftermath of stroke.

Engaging in health promoting activity has been recognized as an important strategy in maintaining independence and quality of life (Parcel *et al.* 1986). However, limited research has addressed family experiences of living with disability, including those associated with stroke, from a health promotion perspective. Consequently, little is known about factors that influence family health promotion behaviours and how participation in such behaviours may influence family members' quality of life. However, the pivotal role of families in the poststroke recovery process suggests the need for attention to their health promotion behaviours. Understanding family health promotion and nurses' role is the focus of the Developmental Model of Health and Nursing (DMHN) (DeMarco *et al.* 2000, Allen & Warner 2002, Ford-Gilboe 2002a), a theoretical extension of the McGill model of nursing (Allen 1983, Gottlieb & Rowat 1987, Gottlieb & Ezer 1997), and the conceptual framework that guided this study.

### Theoretical framework and review of literature

According to the DMHN (see Figure 1), families learn how to be healthy as they experience and deal with life events (Allen & Warner 2002). *Health work*, the central concept in the model, is an active process through which families learn ways of coping and developing that are conducive to healthy living over time (Ford-Gilboe 2002a). *Coping* is viewed as a function of *problem-solving* – a process of attempting to deal with or solve challenging health situations, while *development* relates to *growth-seeking* behaviour seen in the family's ability to mobilize strengths and resources to

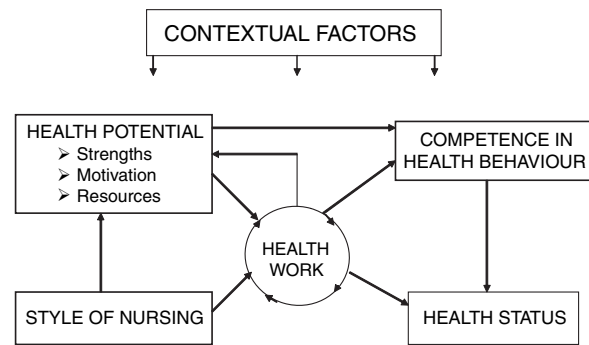


Figure 1 Development Health Model of Health and Nursing (reproduced with permission).

achieve health goals (Allen & Warner 2002, Ford-Gilboe 2002a). Although participation in health work has not been studied in families of stroke survivors, families with chronically ill or disabled members have been found to use varied coping strategies and styles of functioning in response to life events and situations and to engage in healthy lifestyle behaviours to enhance quality of life (Trivette *et al.* 1990, Dezzani-Martin 1995, Stuifbergen 1995).

In the DMHN, *health potential*, the strengths, motivation and resources of the family and its members, is suggested to affect engagement in health work positively (Allen 1983, Allen & Warner 2002, Ford-Gilboe 2002a). *Family strengths* are the internal capabilities of the family and its members that are exhibited as a unique family functioning style (Allen & Warner 2002, Ford-Gilboe 2002a). Although many individual and family strengths have been identified in the literature, few studies have examined the relationships between specific strengths and family health promotion behaviour. One such strength that may facilitate the process of health work, and ultimately improve quality of life, is hope – a basic human response essential for life (Stephenson 1991).

Hope is a complex construct that has received considerable attention in the literature. It has been defined as a multidimensional life force, which is always present to some degree, and is characterized by a confident, yet uncertain, expectation of achieving a future good that is realistically possible and personally significant (Dufault & Martocchio 1985). Hope is thought to exert a positive effect on health by shaping health responses, such as the ability to mobilize necessary resources to achieve goals, thereby improving functioning or, if restoration of functioning is not possible, promoting adaptation to altered functioning (Brown 1989, Piazza *et al.* 1991, Raleigh 1992).

Hope has been studied in a variety of clinical populations, primarily in adults with cancer (Dufault & Martocchio 1985, Herth 1989, 1993, Rustoen 1995, Post-White *et al.* 1996),

but also in people with chronic disease (Raleigh 1992, Beckerman & Northrop 1996) and in healthy populations (Farran *et al.* 1990, Forbes 1994, Morse & Doberneck 1995). In a correlational study of 50 stroke patients undergoing rehabilitation (Popovich 1991), hope was the only significant predictor of functional status, accounting for 14% of the variance. Bays' (1995) qualitative study of nine older stroke survivors revealed that hope was a sustaining force associated with family and spiritual connectedness and goal achievement, similar to Raleigh's (1992) findings in a study of 90 adults with chronic illness. Increased ability to cope (Brown 1989, Herth 1989, Forbes 1994, Fowler 1995) and improved quality of life (Post-White *et al.* 1996, Rustoen *et al.* 1998) have been identified as consequences of hope. However, these studies have not included stroke survivors or their spouses, nor has the relationship between hope and individual or family health promotion behaviours been examined.

In the DMHN, increased competence in health behaviour and improved health status are identified as outcomes of health work (Ford-Gilboe 2002a). *Health status* refers to the functioning of the family and its members, as indicated by concepts such as quality of life, satisfaction with family life, or ability to engage in activities of daily living (Ford-Gilboe 2002a). Quality of life is an individual's perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns [World Health Organization Quality of Life (WHOQOL) Group 1993]. As a multidimensional construct including at least four dimensions – physical, functional, psychological and social (de Haan *et al.* 1992) – quality of life is thought to be situation-dependent and strongly altered by the quality of personal relationships (Peplau 1994). Further, quality of life has been conceptualized as an outcome of goal attainment in individuals, families and society (King 1994).

Although quality of life has become an important outcome measure in stroke research, comparisons of findings between studies have been difficult due to the use of different definitions and measures with various conceptual bases (de Haan *et al.* 1992; Tengs *et al.* 2001). Assessing quality of life has been challenging, given that individuals have different deficits and concurrent psychological and social sequelae (Williams *et al.* 1999). Focussing primarily on people with stroke, and not their caregivers, a number of studies have examined factors associated with quality of life. Personality traits, such as hardiness, self-concept, motivation and family availability and social support (Berk & Schall 1991, Kim *et al.* 1999), depression, anxiety, functional disability (Ahlsio *et al.* 1984, Astrom *et al.* 1992, King 1996, Wyller *et al.* 1997, Lofgren *et al.* 1999, Kauhanen *et al.* 2000), inability to

return to work, and limited leisure opportunities (Niemi *et al.* 1988, Viitanen *et al.* 1988) have been identified as variables associated with quality of life. Among these, depression, functional ability and socialization have been identified as the most significant influences on quality of life (Bays 2001). Most studies have involved people with mild to moderate stroke and with intact cognitive and language functions. It is unclear whether similar factors would affect quality of life in severely impaired stroke survivors. However, in recent studies, individuals with significant impairments have reported acceptable health-related quality of life years after their stroke (King 1996, Lofgren *et al.* 1999, Pilkington 1999, Wyller & Kirkevold 1999, Hackett *et al.* 2000), in some instances exceeding quality of life of those with mild to moderate stroke (Tengs *et al.* 2001).

The experience of family caregivers of stroke survivors has been examined, with most studies emphasizing the negative impact of stroke on caregivers' psychological health, including feelings of burden, stress and clinically significant depression (Dennis *et al.* 1998, Kotila *et al.* 1998, Canam & Acorn 1999, Han & Haley 1999, Wright *et al.* 1999, Blake & Lincoln 2000, King *et al.* 2001), particularly for caregivers of those with significant impairments (Bugge *et al.* 1999). However, some studies have revealed that caregivers, typically women, are satisfied with their lives and have positive feelings about their caregiving roles (Silliman *et al.* 1987, Kinney *et al.* 1995). Factors associated with life satisfaction of caregivers include burden (physical and emotional) related to patients' functional status, changes in social relationships, satisfaction with service provision, and caregivers' appraisal of their capacity to cope (Purk & Richardson 1994, King *et al.* 1995, Kinney *et al.* 1995, Bethoux *et al.* 1996, Hodgson *et al.* 1996, Forsberg-Warleby *et al.* 2001).

## The study

### Aim

Based on the DMHN (Allen & Warner 2002, Ford-Gilboe 2002a), the aim of this study was to examine the relationships among hope, health work and quality of life in families of stroke survivors living with disability. The following hypotheses were tested, as illustrated in Figure 2:

- There is a positive relationship between hope and health work.
- There is a positive relationship between health work and quality of life.
- There is a positive relationship between hope and quality of life.
- Hope and health work predict quality of life.

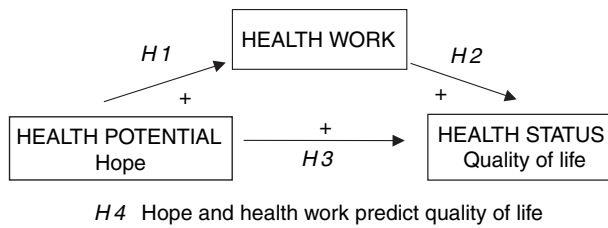


Figure 2 Study hypotheses.

**Design**

A descriptive correlational, cross-sectional design was used since the relationships among hope, health work and quality of life had not been previously studied in the stroke population.

**Participants**

A convenience sample of 40 families in which one member had experienced a stroke was recruited from a midsize city and surrounding county in Southwestern Ontario, Canada. A sample size of 68 families was estimated as needed, using power analysis based on an alpha of 0.05, power of 0.80 and Cohen’s convention for a medium effect (0.30). Given that effect sizes could not be estimated more precisely, interim data analysis was conducted after 40 families had been recruited, revealing substantial relationships between the study variables. Therefore, data collection ceased.

Adult couples who were married or in common-law unions and living together in their own homes were eligible to participate if the stroke survivor had been discharged from a stroke rehabilitation programme for at least 3 months, if both partners were able to understand written and/or verbal information and convey responses in English, and if they consented to participate. People with communication impairments were included if they were able to communicate their responses to the data collector verbally or using alternative methods of communication (e.g. non-verbal, visually-supported approaches, such as gestures, drawings, yes/no). Families meeting the inclusion criteria were identified from the patient list of a stroke rehabilitation programme affiliated with a large Canadian teaching hospital. Of the 52 families who were contacted, 47 (90%) agreed to participate. Prior to data collection seven of these families no longer met the eligibility criteria due to the stroke survivor’s death or health deterioration or relocation to a nursing home, resulting in a final sample of 40 families. Demographic and stroke characteristics of the sample are shown in Tables 1 and 2.

**Table 1** Demographic characteristics of families (n = 40)

Variable	Stroke survivor	Spouse
Age		
Range (years)	46–89	42–89
Mean (SD)	69.5 (9.45)	66.2 (11.21)
Length of relationship		
Range (years)	8–65	
Mean (SD)	39.9 (14.31)	
Education		
High school (%)	45	60
College/University (%)	45	38
Employment		
Working (full- /part-time) (%)	–	20
Unemployed (%)	–	18
Retired (%)	100 (38 – disability)	62
Sex		
Male (%)	73	27
Female (%)	27	73

**Table 2** Stroke characteristics of families (n = 40)

Variable	Range	Mean (SD)
Length of stay (months)	0.6–5.5	3.0 (1.16)
Time from stroke onset	6 months – 5 years	2.5 years (1.66)
FIM		
Admission	27–76	57.3 (16.07)
Discharge	52–119	87.1 (18.87)
FIM change	11–75	30.2 (15.45)
	Frequency	Percentage
Type of stroke		
Ischaemic	25	66
Haemorrhagic	13	34
Deficits		
Aphasia	10	25
Cognitive	26	65
Perceptual	30	75
Visual	21	53
Support (discharge)	36	90
Support (present)	31	78

FIM, functional independence measure.

**Instruments**

The Herth Hope Index (HHI) (Herth 1992) is a 12-item summated rating scale designed as an individual measure of hope. Participants are asked to rate each item using a 4-point Likert response format ranging from strongly disagree (1) to strongly agree (4). The HHI was developed from the 30-item Herth Hope Scale (HHS) (Herth 1991) in an attempt to create a shorter, more clinically useful tool for adults experiencing alterations in health status (Herth 1992). Items for the HHS were generated to reflect Dufault and Martocchio’s (1985) multidimensional concept of hope. The three-dimensional structure of the HHI was supported through factor analysis

(Herth 1992). Internal consistency of HHI in both ill adults and family caregivers has been acceptable (Cronbach's alpha = 0.78–0.97) (Herth 1992, 1993). Test–retest reliability over a 2-week period was 0.91, indicating high stability. In this study, Cronbach's alpha coefficients for total HHI scores were 0.84 for stroke survivors and 0.85 for spouses.

The Health Options Scale (HOS) is a 21-item summated rating scale developed by Ford-Gilboe (1997, 2002b) as a measure of family health work. It uses a 4-point Likert response format ranging from strongly disagree (1) to strongly agree (4). Total scores reflect higher degrees of health work. The three subscale HOS was developed through factor analysis (DeMarco *et al.* 2000, Ford-Gilboe 2002b). Evidence of construct validity has been demonstrated through positive associations between the HOS and Family Hardiness Index ( $r = 0.30$ ) (McGubbin *et al.* 1987), and Problem-Solving Inventory ( $r = -0.35$ ) (Heppner 1988). Acceptable internal consistency for total scores (Cronbach's alpha = 0.86–0.91) has been demonstrated in samples of families with varying structures and socioeconomic backgrounds, including those managing chronic illnesses (DeMarco *et al.* 2000). In our study Cronbach's alpha coefficients for both stroke survivors and their spouses were 0.89.

The 11-item Reintegration to Normal Living Index (RNLI) (Wood-Dauphinee & Williams 1987) was designed to measure the impact of disease or disability on the individual's ability to resume normal patterns of everyday living. Participants are asked to rate their satisfaction with 11 aspects of their physical, emotional and social lives on a series of 100 mm visual analogue scales (VAS) from 'does not describe my situation' (0) to 'fully describes my situation' (100). Each item is scored from 0 to 100 by measuring the distance from 0 to the point on the line where the mark was made in millimetres. Total scores are obtained by summing and averaging responses to individual items, where higher scores represent higher levels of reintegration. Although more limited in its focus than many global quality of life measures, the RNLI includes similar domains (physical, psychological, social) and has, therefore, been proposed as a proxy measure of individual quality of life (Wood-Dauphinee & Williams 1987, Wood-Dauphinee *et al.* 1988). Criterion validity has been established through a positive correlation ( $r = 0.72$ ) between the RNLI and Spitzer's Quality of Life Index (Spitzer *et al.* 1981). Initial testing of the RNLI resulted in high internal consistency (alpha > 0.90) and adequate inter-rater reliability ( $r = 0.62$ – $0.66$ ). In our study, Cronbach's alpha coefficients were 0.92 for stroke survivors and 0.85 for spouses.

A demographic questionnaire was used to collect information about personal and family characteristics of stroke survivors and their spouses, including: age, gender, marital

status, education, employment status, cultural background, family income, and use of community support.

### Data collection

Stroke survivors and their spouses were asked to complete parallel study questionnaires independently in a private setting of their choosing. One partner, typically the spouse, completed a demographic questionnaire on behalf of the family. If necessary, the interviewer assisted stroke survivors who had communication deficits by reading questions to them and/or recording their responses. Questionnaires took 30–40 minutes to complete and a token payment of \$10 per family was given for participation. After completion of the questionnaires, a member of the research team accessed stroke survivors' medical records to collect additional information about stroke characteristics and the rehabilitation stay. Data were collected between July 2001 and January 2002.

### Ethical considerations

The study was approved by the University Ethics Review Board prior to data collection. Participants were provided with detailed information about the study and were assured that confidentiality would be maintained at all times. Written consent was obtained prior to data collection.

### Data analysis

Because the family was the unit of concern in this study, the data were inspected to determine whether scores on the study variables, derived from separate reports provided by stroke survivors and their spouses, could be reasonably aggregated into family level scores. Consistent with the recommendations of Larsen and Olson (1990), the extent of agreement between stroke survivors' and spouses' scores for the variables of hope, health work and quality of life was examined using both correlations and paired *t*-tests (Table 3). While stroke survivors' and spouses' scores for health work and quality of life were moderately related, a weak relationship was found between their ratings of hope. Furthermore, spouses' mean scores for both hope and quality of life were significantly

**Table 3** Correlations and paired *t*-tests between Stroke Survivors' and Spouses' Scores on Study Variables ( $n = 40$ )

Variable	<i>r</i>	<i>P</i> value	<i>t</i>	<i>P</i> value
Hope	0.26	0.05	−2.49	0.017
Health work	0.51	0.00	1.44	0.159
Quality of life	0.57	0.00	−6.3	0.000

higher than stroke survivors' scores for these variables. Since the criteria of no mean difference and moderate correlation ( $>0.30$ ) (Larsen & Olson 1990) were not satisfied for all variables, individual rather than family scores were used in all analyses. Thus, separate tests of the study hypotheses are reported for stroke survivors and their spouses. The level of statistical significance used in all analyses was  $P < 0.05$ .

## Results

Descriptive statistics for main study variables are presented in Table 4. Relatively high levels of hope and health work were found for both stroke survivors and their spouses. Spouses' quality of life was significantly higher than that of stroke survivors. Quality of life was related to many of the same demographic variables for both stroke survivors and spouses. Selected relationships are shown in Table 5. No relationships were found between any of the demographic variables and stroke survivors' reports of hope and health work. Length of the partner relationship was the only demographic variable related to spouses' health work ( $r = 0.31, P = 0.05$ ). Furthermore, a moderate negative relationship ( $r = -0.37, P = 0.02$ ) was found between number of supports at discharge and spouses' level of hope. Gender differences in hope, health work and quality of life were not found for either stroke survivors or spouses.

### Tests of the hypotheses

**Hypothesis 1** (supported): A positive relationship was found between hope and health work for both stroke survivors

( $r = 0.52, P \leq 0.001$ ) and spouses ( $r = 0.39, P = 0.01$ ), although this association was stronger for stroke survivors.

**Hypothesis 2** (supported for stroke survivors but not for spouses): A positive relationship was found between family health work and quality of life reported by stroke survivors ( $r = 0.50, P \leq 0.001$ ). However, no relationship was found between spouses' reports of family health work and their quality of life ( $r = 0.06, P = 0.36$ ).

**Hypothesis 3** (supported): A positive relationship was observed between hope and quality of life for both stroke survivors ( $r = 0.59, P \leq 0.001$ ) and spouses ( $r = 0.32, P = 0.02$ ), although this relationship was stronger for stroke survivors.

**Hypothesis 4** (supported for stroke survivors but not for spouses): hierarchical multiple regression analysis was used to test the hypothesis that hope and health work would predict quality of life. Separate analyses were conducted for stroke survivors and spouses using the same approach. At step 1, spouses' employment status, number of supports at discharge and functional independence at discharge were entered as control variables. Each of these variables was significantly associated with quality of life in both stroke survivors ( $r = 0.39-0.53$ ) and spouses ( $r = 0.32-0.61$ ). Consistent with the DMHN, hope and health work were entered into the equation at step 2.

Results for stroke survivors are presented in Table 6. Due to the small sample size, adjusted  $R^2$ , a more conservative estimate of explained variance than  $R^2$ , is reported. With spouses' employment status, number of supports at discharge and functional independence at discharge entered into the equation (step 1), 40.6% of the variance in stroke survivors' quality of life was explained [ $F(3,32) = 8.98, P < 0.01$ ]. Controlling for the effects of demographic factors, the combination of hope and health work at step 2 contributed an additional 17.8% to explained variance [ $F(2,30) = 7.84, P \leq 0.001$ ]. Thus, with all variables in the equation, 58.4% of the variance in stroke survivors' quality of life was explained [ $F(5,30) = 10.82, P < 0.01$ ]. However, only functional independence at discharge, hope and spouses' employment status contributed unique variance in the final solution obtained, with functional independence at discharge making the strongest contribution.

For spouses, a different pattern of results was observed (Table 7). With spouses' employment status, number of supports at discharge and functional independence at discharge entered into the equation (step 1), 46.3% of the variance in spouses' quality of life was explained [ $F(3,32) = 11.04, P < 0.01$ ]. Controlling for the effects of demographic factors, the combination of hope and health work at step 2 did not contribute additional variance beyond

**Table 4** Descriptive statistics of study variables ( $n = 40$ )

Variable	Stroke survivors			Spouses		
	Range	Mean	SD	Range	Mean	SD
Hope	29-48	37.7	4.46	29-48	39.9	4.73
Health work	51-84	64.6	6.08	49-80	66.1	6.92
Quality of life	12.91-100	65.3	21.26	45.27-100	82.9	14.32

**Table 5** Correlations ( $r$ ) between stroke survivors' and spouses' quality of life and selected demographic variables ( $n = 40$ )

Variable	Quality of life	
	Stroke survivors	Spouses
Supports (discharge)	-0.39*	-0.61*
Length of rehabilitation stay	-0.32*	-0.40*
FIM (discharge)	0.53*	0.32*

\* $P < 0.05$ .

FIM, functional independence measure.

Variables	Multiple R	Adjusted R <sup>2</sup>	R <sup>2</sup> change	F	Beta	t
Step 1	0.676	0.406	0.406	8.98*		
Spouse employment					-0.349	-2.49*
Number of supports					-0.157	-1.09
Discharge FIM					0.518	3.75*
Step 2	0.802	0.584	0.178	7.84*		
Spouse employment					-0.264	-2.21*
Number of supports					-0.074	-0.60
Discharge FIM					-0.414	3.49*
Health work					0.177	1.35
Hope					0.351	2.71*

\* $P < 0.05$ .

FIM, functional independence measure.

Variables	Multiple R	Adjusted R <sup>2</sup>	R <sup>2</sup> change	F	Beta	t
Step 1	0.713	0.463	0.463	11.04*		
Spouse employment					-0.370	-0.278
Number of supports					-0.422	-3.07*
Discharge FIM					0.242	1.84*
Step 2	0.739	0.470	0.007	1.22		
Spouse employment					-0.372	-2.74*
Number of supports					-0.410	-2.92
Discharge FIM					0.265	2.01*
Health work					-0.201	-1.48
Hope					0.140	0.991

\* $P < 0.05$ .

FIM, functional independence measure.

that attributed to the variables entered at step 1. With all variables in the equation, 47% of the variance in spouses' quality of life was explained [ $F(5,30) = 7.20$ ,  $P < 0.01$ ]. Only number of supports at discharge, spouses' employment status and functional independence at discharge made unique contributions to the explained variance in spouses' quality of life, with number of supports and spouses' employment status being the strongest predictors.

## Discussion

This is the first study to highlight the relationships among family strengths, health promotion behaviours and quality of life in a stroke sample. The theoretical relationships in the DMHN were validated for stroke survivors. However, only two of four hypotheses were supported using data from spouses. Thus, the theory was less useful in explaining spouses' experiences of hope, health work and quality of life.

The positive relationship found between hope and health work for both partners is not surprising, given that hope is a positive force that enhances motivation, goal achievement and adaptation (Piazza *et al.* 1991, Raleigh 1992). Both

stroke survivors and their spouses reported relatively high levels of hope, suggesting that this capacity was available to them. People with stroke and their caregivers have been found to experience a range of challenges in the recovery period that may tax their ability to manage multiple demands and deplete their energy (Kinney *et al.* 1995, Bugge *et al.* 1999, Canam & Acorn 1999, Clarke *et al.* 1999, Han & Haley 1999). Given the sustaining and energy-generating nature of hope (Bays 1995), those who are more hopeful may have greater incentives and energy to draw upon, and this may help motivate them to participate more actively in problem-solving and growth-seeking behaviours in spite of ongoing challenges.

Consistent with previous research in other clinical populations (Rustoen 1995, Post-White *et al.* 1996, Rustoen *et al.* 1998), our results suggest that stroke survivors and their spouses who were more hopeful also experienced higher quality of life, and that both partners perceived their quality of life to be fairly high, despite living with disability. It has been suggested that hope and quality of life share elements of interconnectedness, realistic expectations and personal relevance (Rustoen 1995). As stroke survivors and their spouses continue to strive towards a positive future that is meaningful

**Table 6** Hierarchical multiple regression of stroke survivors' quality of life on hope, health work and selected demographic variables ( $n = 40$ )

**Table 7** Hierarchical multiple regression of spouses' quality of life on hope, health work and selected demographic variables ( $n = 40$ )

to them, the hope they experience may transcend all aspects of their lives. This supports the notion that living with disability, although a life-altering experience, may be perceived in positive terms, as long as personally relevant outcomes are obtained, not only in families of stroke survivors with mild to moderate impairments but also in those with more significantly affected individuals. Thus, it is not surprising that those who are more hopeful are more likely to place a more positive value on their life quality.

The observation that family health work was positively related to quality of life for stroke survivors but not for spouses may be explained in several ways. Although the RNLI includes physical, psychological and social components, as do the majority of measures assessing quality of life, it is more limited in focus because it concentrates on functional status (Wood-Dauphinee & Williams 1987). It is possible that the RNLI did not capture key dimensions of quality of life for spouses, and therefore may have been less appropriate for them. Accordingly, recent studies have used the RNLI to assess quality of life of stroke survivors, but not their spouses (Bethoux *et al.* 1996, 1999). Furthermore, the majority of spouses were women who assumed caregiving responsibilities for their partners. Caregiving may be considered one context in which health work is undertaken. Given both the level of disability of their partners and the fact that women are traditionally the health guardians of their families, it is likely that spouses assumed the primary responsibility for developing and maintaining health work. Given also the substantial body of literature that documents the high personal demands of caregiving (Scholte op Reimer *et al.* 1998, Han & Haley 1999, Van den Heuvel *et al.* 2001), it is possible that spouses felt burdened in their efforts to sustain family health work, and this may explain the absence of relationship between health work and quality of life. In contrast, given stroke survivors' level of disability, it is possible that they put less effort into maintaining family health work, yet obtained the benefits in terms of their quality of life. Although research is limited in this area, Moore-Hepburn also found a weak relationship ( $r = 0.24$ ) between health work and quality of life of people with inflammatory bowel disease, the majority ( $n = 35$ , 58%) of whom were employed adult mothers caring for their dependent children (DeMarco *et al.* 2000).

The most important predictor of stroke survivors' quality of life was their degree of functional independence at discharge, followed by hope and spouses' employment. Clearly, those who were more independent, more hopeful and whose spouses were not working reported better quality of life. It has been suggested that disability does not preclude having reasonable quality of life, yet higher levels

of functional independence may make it easier for stroke survivors to achieve greater life satisfaction, depending on the meaning they ascribe to their lives. A somewhat different pattern of findings was observed for spouses, whose quality of life was not predicted by hope and health work but by the number of supports and functional independence of their partner at discharge and their current employment status. Spouses who were not working, whose partners were more independent and received fewer supports at discharge, reported better quality of life. These findings suggest that illness-related, social and economic factors may be more important contributors to spouses' quality of life than perception of hope and health promotion behaviours. Functional disability of stroke survivors has been consistently associated with caregiver burden and life satisfaction in previous studies (Purk & Richardson 1994, King *et al.* 1995, Bethoux *et al.* 1996, Forsberg-Warleby *et al.* 2001). Thus, given greater functional independence of stroke survivors, their spouses are likely to have experienced reduced caregiver burden and, in turn, higher perceived quality of life.

Although different sets of variables predicted quality of life of stroke survivors and their spouses, two factors – stroke survivors' functional independence at discharge and spouses' employment – were common predictors of quality of life for both partners. Patients' discharge home has been predicted by both their functional status and family availability and support (Black *et al.* 1999). As employed spouses juggle their daily caregiving responsibilities and job demands, they may be less available to their partners. The associated role overload and strain may result in greater caregiver burden (Edwards *et al.* 2002) and decreased quality of life for both partners. Consistent with previous research, the majority of caregivers in this study were women. In the context of societal and family norms and expectations that reinforce women's roles as 'natural caregivers', women continue to shoulder more responsibility for caregiving than men and, subsequently, are more likely to experience negative effects of caregiving on their health and everyday lives, including paid work (Morris 2001). For example, the ongoing and sometimes conflicting demands associated with multiple roles contribute to both stress (Jenkins 1997) and burnout (van den Heuvel *et al.* 2001) in female caregivers.

### Study limitations

One should consider the following limitations when assessing the relevance of study findings: a) use of a correlational design resulting in the inability to infer causality; b) limited

### What is already known about this topic

- The major focus has been on negative implications of stroke and caregiver burden, and there is limited knowledge of strengths that help families meet the challenges of stroke recovery.
- Limited research exists on hope and health promotion in families living with disability, including following stroke.
- Stroke has been found to affect quality of life negatively in families of stroke survivors, but it is difficult to compare findings due to the use of quality of life measures with various conceptual bases.

### What this paper adds

- An examination of the relationships between hope, health work and quality of life in families of stroke survivors.
- The relatively high levels of hope, health work and quality of life for both partners suggest that living with disability may evolve into a positive experience, even in the face of significant impairment.
- Focusing interventions on families' strengths, improving functional outcomes and paying attention to illness-related, social and economic factors as important contributors to quality of life are highlighted for rehabilitation clinicians.
- It is important to consider caregiver burden when assessing quality of life after stroke, particularly for employed caregivers.

generalizability due to the relatively small convenience sample; c) the accuracy of stroke survivors' responses may have been compromised by the complexity of their communication deficits; and d) lack of support for two of the study hypotheses for spouses may have been due to inadequate statistical power or to the use of the RNLI to assess spouses' quality of life.

### Implications

Bearing in mind its limitations this study may have implications for rehabilitation teams working with stroke survivors and their families:

- Given that stroke survivors and their spouses may be living two different realities, it is critical that clinicians consider each partner's experience in designing interventions that support quality of life.

- Patient outcomes, including quality of life, may be improved if clinicians identify and build on the strengths of stroke survivors and their spouses, including their sense of hope, rather than focussing on their deficits and the challenges they face.
- As part of an interdisciplinary assessment, the Herth Hope Index (HHI) may be a useful clinical tool for assessing hope in both stroke survivors and their spouses. Similarly, the RNLI can be used to assess quality of life in stroke survivors, but a different quality of life tool should be used for spouses.
- Study findings provide direction in identifying families in which stroke survivors or spouses may be at risk for poor quality of life post-discharge. In both discharge planning and community follow-up, additional resources may be needed in families with employed spouses or significantly impaired stroke survivors in order to promote quality of life.
- Given that economic challenges and limited resources in the community may negatively impact caregivers' quality of life, these issues must be considered in planning for ongoing family support. Nurses and other health professionals have an important political role to play in raising awareness about current gaps in community resources and in advocating for viable solutions to system problems so that families may attain a reasonable quality of life after stroke.

A number of research implications can also be suggested:

- Many of the study participants expressed a desire to 'tell their stories', in addition to completing the required structured questionnaires. Qualitative studies are warranted to understand better the complexity of family experiences after stroke.
- It is important to continue examining both positive and negative aspects of caregiving to further address issues related to caregivers' quality of life.
- The sustainability and generalizability of findings can be further determined if similar relationships are studied prospectively in a larger, more heterogeneous sample.

### Conclusion

This study contributes to the knowledge base about health promotion and quality of life issues in stroke survivors and their spouses. The importance of rehabilitation interventions in stroke populations is supported. Clinicians can gain greater insight into how living with disability may evolve into a positive experience, even in the face of significant impairment.

### Acknowledgements

This study was supported by a research grant from the Parkwood Hospital Foundation and the Nursing Research Interest Group (NRIG) of Registered Nurses Association of

Ontario (RNAO). Special thanks to Kathy Draudt for her assistance with data collection.

## References

- Ahlsio B., Britton M., Murray V. & Theorell T. (1984) Disablement and quality of life after stroke. *Stroke* **15**, 886–890.
- Allen M. (1983) Primary care nursing: research in action. In *Recent Advances in Nursing: Primary Care Nursing* (Hockey L., ed.), Churchill-Livingstone, Edinburgh, pp. 32–77.
- Allen M. & Warner M. (2002). A Developmental Model of Health and Nursing. *Journal of Family Nursing* **8**, 96–135.
- Anderson C., Linto J. & Stewart-Wynne E. (1995) A population-based assessment of the impact and burden of caregiving for long-term stroke survivors. *Stroke* **26**, 843–849.
- Astrom M., Asplund K. & Astrom T. (1992) Psychosocial function and life satisfaction after stroke. *Stroke* **23**, 527–531.
- Bays C. (1995) *Older adults descriptions of hope after a stroke*. PhD Thesis, University of Cincinnati, Cincinnati.
- Bays C. (2001) Quality of life of stroke survivors: a research synthesis. *Journal of Neuroscience Nursing* **33**, 310–316.
- Beckerman A. & Northrop C. (1996) Hope, chronic illness and the elderly. *Journal of Gerontological Nursing* **22**, 19–25.
- Berk S. & Schall R. (1991) Psychosocial factors in stroke rehabilitation. Crucial factors for successful outcome. *Physical Medicine and Rehabilitation Clinics of North America* **2**, 547–561.
- Bethoux F., Calmels P., Gautheron V. & Minaire P. (1996) Quality of life of the spouses of stroke patients: a preliminary study. *International Journal of Rehabilitation Research* **19**, 291–299.
- Bethoux F., Calmels P. & Gautheron V. (1999) Changes in the quality of life of hemiplegic stroke patients with time. A preliminary report. *American Journal of Physical Medicine and Rehabilitation* **78**, 19–23.
- Black T., Soltis T. & Bartlett C. (1999) Using the functional independence measure instrument to predict stroke rehabilitation outcomes. *Rehabilitation Nursing* **24**, 109–114.
- Blake H. & Lincoln, N. (2000) Factors associated with strain in co-resident spouses of patients following stroke. *Clinical Rehabilitation* **14**, 307–314.
- Brown P. (1989) The concept of hope: implications for care of the critically ill. *Critical Care Nurse* **9**, 97–105.
- Bugge C., Alexander H. & Hagen S. (1999) Stroke patients' informal caregivers. Patient, caregiver, and service factors that affect caregiver strain. *Stroke* **30**, 1517–1523.
- Canam C. & Acorn S. (1999) Quality of life for family caregivers of people with chronic health problems. *Rehabilitation Nursing* **24**, 192–196.
- Clarke P., Black S., Badley E., Lawrence J. & Williams J. (1999) Handicap in stroke survivors. *Disability and Rehabilitation* **21**, 116–123.
- DeMarco R., Ford-Gilboe M., Friedman M., McCubbin H. & McCubbin M. (2000) Stress, coping and family health. In *Handbook of Stress, Coping and Health* (Rice V.H., ed.), Sage Publications, Thousand Oaks, CA, pp. 295–332.
- Dennis M., O'Rourke S., Lewis S., Sharpe M. & Warlow C. (1998) A quantitative study of the emotional outcome of people caring for stroke survivors. *Stroke* **29**, 1867–1872.
- Dezzani-Martin S. (1995) Coping with chronic illness. *Home Healthcare Nurse* **13**, 50–54.
- Dufault K. & Martocchio B. (1985) Hope: its spheres and dimensions. *Nursing Clinics of North America* **20**, 379–391.
- Edwards A., Zarit S., Stephens M. & Townsend A. (2002) Employed family caregivers of cognitively impaired elderly: an examination of role strain and depressive symptoms. *Aging and Mental Health* **6**, 55–61.
- Farran C., Salloway J. & Clark D. (1990) Measurement of hope in a community-based older population. *Western Journal of Nursing Research* **12**, 42–59.
- Forbes S. (1994) Hope: an essential human need in the elderly. *Journal of Gerontological Nursing* **20**, 5–10.
- Ford-Gilboe M. (1997) Family strengths, motivation and resources as predictors of health promotion behavior in single-parent and two-parent families. *Research in Nursing and Health* **20**, 205–217.
- Ford-Gilboe M. (2002a) Developing knowledge about family health promotion by testing the Developmental Model of Health and Nursing. *Journal of Family Nursing* **8**, 140–156.
- Ford-Gilboe M. (2002b) Development and testing a measure of family health promotion behaviour: the Health Options Scale (in press).
- Forsberg-Warley G., Moller A. & Blomstrand C. (2001) Spouses of first-ever stroke patients: psychological well-being in the first phase after stroke. *Stroke* **32**, 1646–1651.
- Fowler S. (1995) Hope: implications for neuroscience nursing. *Journal of Neuroscience Nursing* **27**, 298–304.
- Gottlieb L. & Ezer H. (ed.) (1997) *A Perspective on Health, Family, Learning and Collaborative Nursing*. McGill University, Montreal.
- Gottlieb L. & Rowat K. (1987) The McGill model of nursing: a practice-derived model. *Advanced Nursing Science* **9**, 51–61.
- de Haan R., Aaronson N., Limburg M., Hewer R.L. & van Crevel H. (1992) Measuring quality of life in stroke. *Stroke* **24**, 320–327.
- Hackett M., Duncan J., Anderson C., Broad J. & Bonita R. (2000) Health-related quality of life among long-term survivors of stroke. *Stroke* **31**, 440–447.
- Han B. & Haley W. (1999) Family caregiving for patients with stroke. Review and analysis. *Stroke* **30**, 1478–1485.
- Heart and Stroke Foundation of Ontario (2002) Selected brochures. Available at: <http://www.heartandstroke.ca>
- Heppner P. (1988) *The Problem Solving Inventory*. Consulting Psychologists Press, Palo Alto, CA.
- Herth K. (1989) The relationship between level of hope and level of coping response and other variables in patients with cancer. *Oncology Nursing Forum* **16**, 67–72.
- Herth K. (1991) Development and refinement of an instrument to measure hope. *Scholarly Inquiry for Nursing Practice: An International Journal* **5**, 39–51.
- Herth K. (1992) Abbreviated instrument to measure hope: development and psychometric evaluation. *Journal of Advanced Nursing* **17**, 1251–1259.
- Herth K. (1993) Hope in the family caregiver of terminally ill people. *Journal of Advanced Nursing* **18**, 538–548.
- Hodgson S., Wood V. & Langton-Hewer R. (1996) Identification of stroke carers "at risk": a preliminary study of the predictors of carers' psychological well-being at one year post-stroke. *Clinical Rehabilitation* **10**, 337–346.
- Jenkins C. (1997) Women, work and caregiving: how do these roles affect women's well-being? *Journal of Women and Aging* **9**, 27–45.

- Kauhanen M., Korpelainen J., Hiltunen P., Nieminen P., Sotaneimmi K. & Myllyla V. (2000) Domains and determinants of quality of life after stroke caused by brain infarction. *Archives of Physical Medicine and Rehabilitation* 81, 1541–1546.
- Kim P., Warren S., Madill H. & Hadley M. (1999) Quality of life of stroke survivors. *Quality of Life Research* 8, 294–301.
- King I. (1994) Quality of life and goal attainment. *Nursing Science Quarterly* 7, 29–32.
- King R. (1996) Quality of life after stroke. *Stroke* 27, 1467–1472.
- King R., Shade-Zeldow Y., Carlson C., Knafelz K. & Roth E. (1995) Early adaptation to stroke: patient and primary support person. *Rehabilitation Nursing Research* 4, 82–89.
- King R., Carlson C., Shade-Zeldow Y., Bares K., Roth E. & Heinemann A. (2001) Transition to home care after stroke: depression, physical health, and adaptive processes in support persons. *Research in Health and Nursing* 24, 307–323.
- Kinney J., Stephens M., Franks M. & Norris V. (1995) Stress and satisfaction of family caregivers of older stroke patients. *Journal of Applied Gerontology* 14, 3–21.
- Kotila M., Numminen H., Waltimo O. & Kaste M. (1998) Depression after stroke: results of the FINNSTROKE study. *Stroke* 29, 368–372.
- Larsen A. & Olson D. (1990) Capturing the complexity of family systems: integrating family theory, family scores and family analysis. In *Family Variables: Conceptualization, Measurement and Use* (Draper T. & Marcos M., eds), Sage, Newbury Park, CA.
- Lofgren B., Gustafson Y. & Nyberg L. (1999) Psychological well-being 3 years after severe stroke. *Stroke* 30, 567–572.
- McGubbin M., McGubbin H. & Thompson A. (1987) Family Hardiness Index. In *Family Assessment Inventories for Research and Practice* (McGubbin H. & Thompson A., eds), University of Wisconsin, Madison, WI, pp. 125–130.
- Morris M. (2001) *Gender-Sensitive Home and Community Care and Caregiving Research: A Synthesis Paper*. Women's Health Bureau, Home and Continuing Care, Status of Women, Health Canada, Ottawa, ON.
- Morse J. & Doberneck B. (1995) Delineating the concept of hope. *Image: Journal of Nursing Scholarship* 27, 277–285.
- Niemi M., Laaksonen R., Kotila M. & Waltimo O. (1988) Quality of life 4 years after stroke. *Stroke* 19, 1101–1107.
- Parcel G., Barlett E. & Bruhn J. (1986) The role of health education in self-management. In *Self-Management of Chronic Disease* (Holroyd K.A. & Creer T.L., eds), Academic Press, Orlando, FL, pp. 3–27.
- Peplau H. (1994) Quality of life: an interpersonal perspective. *Nursing Science Quarterly* 7, 10–15.
- Piazza D., Holcombe J., Foote A., Paul P., Love S. & Daffin P. (1991) Hope, social support and self-esteem of patients with spinal cord injuries. *Journal of Neuroscience Nursing* 23, 224–230.
- Pilkington F. (1999) A qualitative study of life after stroke. *Journal of Neuroscience Nursing* 31, 336–347.
- Popovich J. (1991) *Hope, Coping and Rehabilitation Outcomes in Stroke Patients*. College of Nursing, Rush University, Chicago, IL.
- Post-White J., Ceronisky C., Kreitzer M., Nickelson K., Drew D., Mackey K., Koopmeiners L. & Gutknecht S. (1996) Hope, spirituality, sense of coherence, and quality of life in patients with cancer. *Oncology Nursing Forum* 23, 1571–1579.
- Purk J. & Richardson R. (1994) Older adults stroke patients and their spousal caregivers. *Family Sociology* 75, 608–615.
- Raleigh E. (1992) Sources of hope in chronic illness. *Oncology Nursing Forum* 19, 443–448.
- Rustoen T. (1995) Hope and quality of life, two central issues for cancer patients: a theoretical analysis. *Cancer Nursing* 18, 355–361.
- Rustoen T., Wiklund L., Hanestad B. & Moum T. (1998) Nursing intervention to increase hope and quality of life in newly diagnosed cancer patients. *Cancer Nursing* 21, 235–245.
- Scholte op Reimer W., de Haan R., Rijnders P., Limburg M. & van den Bos G.A.M. (1998) The burden of caregiving in partners of long-term stroke survivors. *Stroke* 29, 1605–1611.
- Silliman R., Earp J., Flecher R. & Wagner E. (1987) Stroke: the perspective of family caregivers. *Journal of Applied Gerontology* 5, 363–371.
- Spitzer W., Dobson A., Hall J., Chesterman E., Levi J., Shepherd R., Battista R. & Catchlove B. (1981) Measuring quality of life of cancer patients: concise QL-Index for use by physicians. *Journal of Chronic Disability* 34, 585–597.
- Stephenson C. (1991) The concept of hope revisited for nursing. *Journal of Advanced Nursing* 16, 1456–1461.
- Stuifbergen A. (1995) Health-promoting behaviours and quality of life among individuals with multiple sclerosis. *Scholarly Inquiry for Nursing Practice* 9, 31–55.
- Tengs T., Yu M. & Luistro E. (2001) Health-related quality of life after stroke: a comprehensive review. *Stroke* 32, 964–972.
- Trivette C., Dunst C., Deal A., Hamer A. & Propst S. (1990) Assessing family strengths and family functioning style. *Topics in Early Childhood Special Education* 10, 16–35.
- Van den Heuvel E., de Witte L., Schure L., Sanderman R. & Meyboom-de Jong B. (2001) Risk factors for burn-out in caregivers of stroke patients, and possibilities for intervention. *Clinical Rehabilitation* 15, 669–677.
- Viitaniemi M., Fugl-Meyer K., Bernspang B. & Fugl-Meyer A. (1988) Life satisfaction in long-term survivors after stroke. *Scandinavian Journal of Rehabilitation Medicine* 20, 17–24.
- WHOQOL Group (1993) Study protocol for the World Health Organization project to develop quality of life assessment instrument (WHOQOL). *Quality of Life Research* 2, 153–159.
- Williams L., Weinberger M., Harris L., Clark D. & Biller J. (1999) Development of a stroke-specific quality of life scale. *Stroke* 30, 1362–1369.
- Wood-Dauphinee S. & Williams J. (1987) Reintegration to normal living as a proxy to quality of life. *Journal of Chronic Disability* 40, 491–499.
- Wood-Dauphinee S., Opzommer M., Williams J., Marchand B. & Spitzer W. (1988) Assessment of global function: the reintegration to Normal Living Index. *Archives of Physical Medicine and Rehabilitation* 69, 583–590.
- Wright L., Hickey J., Buckwalter K., Hendrix S. & Kelechi T. (1999) Emotional and physical health of spouse caregivers of persons with Alzheimer's disease and stroke. *Journal of Advanced Nursing* 30, 552–563.
- Wyller T. & Kirkevold M. (1999) How does a cerebral stroke affect quality of life? Towards an adequate theoretical account. *Disability and Rehabilitation* 21, 152–161.
- Wyller T., Svein U., Sodring K., Pettersen A. & Bautz-Holter E. (1997) Subjective well-being one year after stroke. *Clinical Rehabilitation* 11, 139–145.