SOCIAL ASPECTS OF THE DELIVERY OF CARE

Lifestyle as a Health Risk for Family Caregivers with Least Life Satisfaction, in Home-Based Post-Stroke Caring

Dans les soins à domicile qui font suite à un accident vasculaire cérébral, le mode de vie des aidants familiaux présentant une moindre satisfaction à l'égard de la vie est un facteur de risque pour leur santé

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Abstract

Our purpose was to clarify that caregiving roles represent a situation of risk for the health of family caregivers, in home-based caring two years after cerebrovascular disease. Our aim was to determine the social and emotional repercussions of the event on family caregivers. Family caregivers living at home with stroke survivors were identified by a national survey. The Life Satisfaction (LS) national indicator for Luxembourg is 7.9/10, while in Canada it stands at 7.7. Caregivers with a LS level ≤ 7 were more likely to care for survivors affected by motor, sensory and memory neurological impairments. For a great majority, these impairments led to serious upheaval among families, and for spouses it was "a drama." For family caregivers with a least life satisfaction, their lifestyle poses a real health risk for the public health system.

Résumé

Notre propos a été de mettre en lumière que le rôle d'aidant représente une situation à risque pour la santé des aidants familiaux dans les soins à domicile, deux ans après un accident vasculaire cérébral (AVC). Notre objectif a été de déterminer les répercussions sociales et émotionnelles de l'évènement chez les aidants familiaux. Les aidants familiaux vivant à leur domicile avec les victimes d'un AVC ont été identifiés lors d'une enquête nationale. L'indicateur national de SV du Luxembourg étant de 7,9/10 (en comparaison d'avec le Canada qui obtient 7,7), les aidants avec un niveau de satisfaction à l'égard de la vie (SV) ≤ 7 sont plus nombreux à s'occuper de victimes atteintes d'affections neurologiques motrices, sensorielles et de la mémoire. Pour une grande majorité, cet accident a entrainé de sérieux bouleversements dans leur famille, et pour les conjoints, ce fut "un drame." Pour les aidants familiaux avec un degré moindre de SV, leur mode de vie contient un réel risque sanitaire pour le système de santé publique.

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Cerebrovascular diseases are an important public health policy concern because of their high prevalence and the long-term disability that survivors often experience; it is the principal acquired cause of handicap, and one of the most common causes of death in countries such as Luxembourg and Canada (WHO 2010). In the present economic climate, in which costly in-patient rehabilitation is giving way to home-based healthcare (Jungbauer et al. 2008), lifestyle-related risks (Massé 2007), as well as the positive experiences of home caregivers (Han and Haley 1999), require investigation. Stroke patients and family caregivers tend to have a relatively short time to get used to their new situation (Green and King 2007), in which the unexpected health circumstances and specific family issues affect satisfaction with life as a whole (Bergstöm et al. 2011). For Frohlich and Poland (2006), lifestyles reflect the interrelations between orientations, resources and health behaviours adopted by groups of individuals in response to their social, cultural and economic environment.

In Canada, nearly half of family caregivers of stroke patients are at risk of developing psychological and social issues (Teasell et al. 2009). These individuals, who have suffered lasting changes as a result of cerebrovascular disease, are significantly challenged to maintain high life satisfaction, defined as a global measure of the degree of discrepancy between individual aspirations and achievements, or general contentment. The Conference Board of Canada (2013) and the European Foundation for the Improvement of Living and Working Conditions (2010) find the monitoring of the social progress of citizens, as well as their position in society, to be important in informing public health policies. The Grand Duchy of Luxembourg is one of the smallest countries in Europe, yet has a very high gross domestic product (GDP) per inhabitant ($107,476 vs. $52,219 in Canada) (World Bank 2012). Along with Canada, Luxembourg is among the top countries in terms of life satisfaction, with a score of 7.9 (Conference Board of Canada 2013; European Foundation 2010). A recent study showed that, two years post-stroke, family caregivers' life satisfaction was positively associated with survivors' quality-of-life dimensions of feelings (less independent, life changed, depressed, useless, less control because of stroke) and emotion (get more emotional, fear of another stroke or of becoming dependent on others), and with their own quality of life (Baumann et al. 2012b). Life satisfaction after a stroke has been considered a significant issue in rehabilitation for care recipients (Low et al. 1999) and also for family members.

Taking a micro-sociological approach, we intended to explore whether home care for stroke survivors is a good idea if the repercussions create a lifestyle that represents a health risk for family caregivers. If the needs, resources, skills and will of the family caregivers for "taking care of the other" are hardly taken into account, the questions for the future are: How can the physical and psychological exhaustion of family caregivers be prevented? How might this change be approached in a positive way, as for instance, with innovative initiatives, involvement of the private sector or other forms of support, or services for caregivers that include opportunities for exchange of competences and resources?

Caregivers who have low life satisfaction also have lower health-related quality of life, a greater prevalence of stress and depression, more economic problems and an impoverished social life (Brännholm et al. 1996). As with the interconnectedness of other couple-related factors, such as emotional well-being, the quality of a couple's interpersonal relationship and the way they cope together with life problems are positively associated with the life satisfaction of each partner (McCarthy et al. 2011). Studies have shown that couples who are dissatisfied with life perceive a greater level of caregiving burden compared to couples in which both spouses are satisfied (Ekstam et al. 2010).

During the first year post-stroke, spouses caring for male survivors reported lower life satisfaction (Forsberg-Wärleby et al. 2004) and were more often depressed than women caregivers generally (Berg et al. 2005). In addition, spouses or companion caregivers faced with physical, psychosocial and emotional problems are more exposed to burnout, particularly if they are women and if they are older (Navaie-Waliser et al. 2002). Women believe that their families let them care alone for the stroke-patient relative, making it difficult to find relevant help, which would in turn have a considerable impact on their own health (Bucki et al. 2012).

Factors already identified as associated with low caregiver life satisfaction include care recipient with physical and cognitive impairments (Forsberg-Wärleby et al. 2004), a decline in the caregiver's health due to caregiving demands (Forsberg-Wärleby and Möller 2001) and couples failing to adapt to the post-stroke situation at home (Green and King 2007). For example, one year post-stroke, life satisfaction was found to decline for patients (because of motor impairments, limitations in daily activities and post-event depression) and increase for those family caregivers who reintegrated into normal patterns of living and gained confidence in their healthcare work (Ostwald et al. 2009).

Studying individuals two years post–cerebrovascular disease creates an opportunity to gather valuable information on the survivor–caregiver dyad over time. In the chronic phase, patients and their family caregivers may have reorganized their daily lives and become accustomed to caregiving. Some studies of home-based stroke healthcare showed that caring for patients has an impact on family caregivers' life satisfaction, and analyzed the stroke-related impact on the patient–caregiver couple relationship (Green and King 2007) and the factors associated with caregiving that affect spouse–caregivers' life satisfaction (Carlsson et al. 2007; Ostwald et al. 2009).

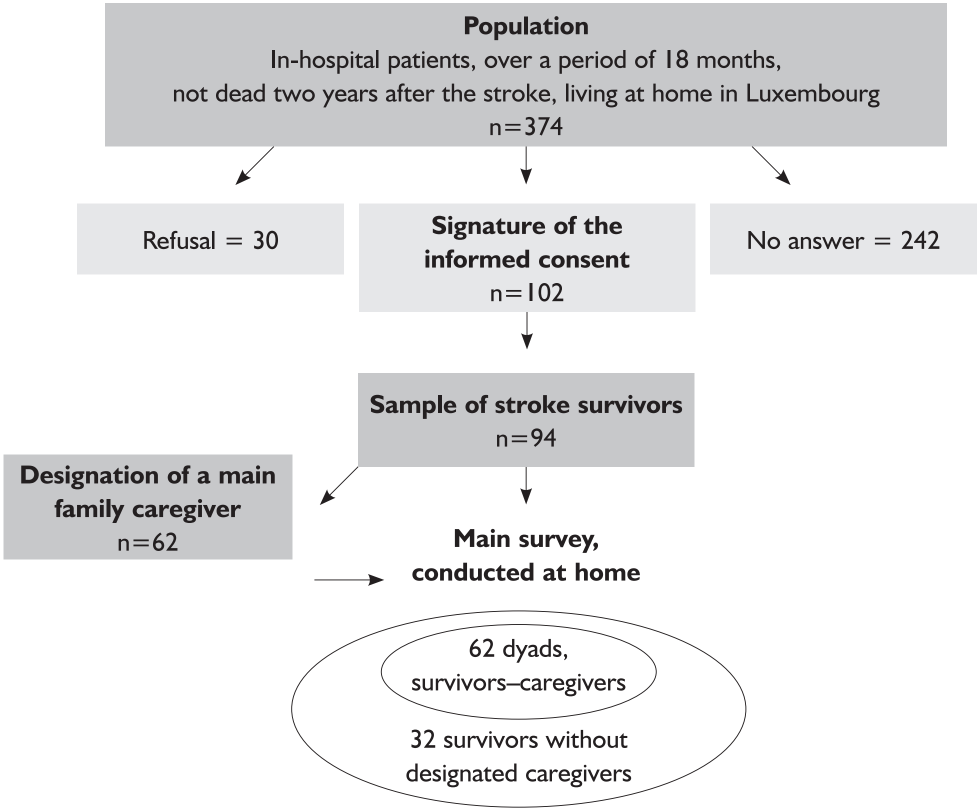
The strength of our project relies on the application of a self-assessment instrument to measure life satisfaction, as previously used in quality-of-life surveys, as well as the impact of the stroke on social lives and the experience of the caregiving role. Our aim was to determine the emotional and social repercussions of stroke on family caregivers with low life satisfaction, their sociodemographic characteristics and the associated neurological impairments of the survivors two years after cerebrovascular disease.

Methods

Participants and procedures

Over a period of 18 months, all stroke survivors (797 patients) admitted to all hospitals in Luxembourg and living at home two years post-stroke were identified from the *Inspection générale de la sécurité sociale*, the only relevant national database (see Figure 1).

FIGURE 1. Design of the national Luxembourg study



We sent a letter to 374 patients who lived at home, explaining the aims of the survey and inviting them to participate. The consents of the main family caregivers were obtained when the research teams went to the stroke survivors' homes to undertake the survey. After receiving each patient's signed informed consent, the research team telephoned to make an appointment at the patient's home with the main caregiver whom he or she had identified as "the person who mostly takes care of [the patient] since the stroke event."

As Luxembourg is a multilingual country, our questionnaires were written in five languages. Most of the instruments were already validated in French or English. The German, Portuguese and Luxembourgish versions were translated, back-translated and proofread by native-speaking professional translators.

Data collected from patients

The Life Satisfaction (LS) Scale provides a subjective appraisal by asking respondents to self-rate their LS: "On a scale of 1 to 10, where would you place your level of satisfaction with your life?" (10 being the highest level).

Neurological impairments and residual disabilities, as formulated by the American Heart Association Stroke Outcome Classification (AHA.SOC), is a validated system that synthesizes stroke-related problems in single summary scores (Kelly-Hayes et al. 1998). Deficiencies were documented in motor, sensory, vision, cognition, language function, continence and memory abilities, and in personality disorder.

Sociodemographic characteristics (see Table 1) were collected for mean age, sex, educational level, occupation at the time of stroke and current occupational status.

Data collected from family caregivers

With regard to life satisfaction and socio-economic characteristics, the same tools and procedures as for the survivors were applied; information about the relationship with the care recipient (i.e., spouse/partner or other) was added.

The experience of caregiving (see Table 2) was gauged using the items of the Caregiver Reaction Assessment instrument (Given et al. 1992 for the English version; Antoine et al. 2010 for the French version), which explores caregiver esteem, lack of family support, financial strain, impact of caregiving on scheduled activities and health problems.

Family and couple relationships (see Table 3) were assessed based on a previous qualitative study (Baumann and Aïach 2009). The items covered were disruptions within the family relationship and changes in the distribution of roles within the couple.

TABLE 1. Sociodemographic and stroke-related characteristics: mean (standard deviation) and percentage

				LS groups of family caregivers		
		Patients n=62	**Family caregivers n=62**	**LS ≤7 n=31**	**LS >7 n=31**	***p***
Age		64.4 (15.8)	59.3 (13.7)	59.1 (12.2)	59.3 (15.1)	0.962
Sex	Women	40.3	65.6	75.9	55.2	0.167
	Men	59.7	34.4	24.1	44.8	
Relationship with survivor	Spouse / Partner	–	82.3	79.3	92.6	0.254
	Child / Other	–	17.7	20.7	7.4	
Educational level	Under 12th grade	44.4	42.4	48.3	34.5	0.424
	12th grade and above	55.6	57.6	51.7	65.5	
Occupation at the time of stroke[1]	Never employed	20.4	17.5	21.4	14.3	0.328
	Manual worker	22.2	14.0	21.4	7.1	
	Employee / Intermediate professional / Technician	35.2	49.1	42.9	53.6	
	Manager / Liberal profession	22.2	19.3	14.3	25.0	
Occupational status, two years post-stroke	Working	19.6	35.6	31.0	42.9	0.650
	At home without activity	23.2	30.5	32.1	24.1	–
	Retired	57.1	33.9	37.9	32.1	–
Current AHA.SOC[2] impaired functions and disabilities	Motor	43.5		65.5	27.6	0.008**
	Visual	22.6		27.6	20.7	0.760
	Sensory	53.2		69.0	41.4	0.064§
	Language	32.3		41.4	27.6	0.408
	Memory	38.7		55.2	27.6	0.061§
	Personality disorder	22.6		31.0	17.2	0.358
	Incontinence	14.5		20.7	10.3	0.470

p: Significance level (§ ≤0.1; * ≤0.05; ** ≤0.01; *** ≤0.001).

[1] For unemployed and retired people as well as for those in vocational training at the time of the event, the last occupational activity was recorded.

[2] American Heart Association Stroke Outcome Classification (AHA.SOC) (Kelly-Hayes et al. 1998).

Statistical analysis

According to the mean Luxembourg LS value (7.9), two groups were built: one with the respondents having a LS ≤7 versus the other with a level >7. Quantitative variables were compared using the Student's t-test or the Mann-Whitney test, and the categorical variables using the Fisher's exact test. Percentages indicate the proportions of those answering "completely agree" or "agree."

Results

The participation rate was 94/374 = 25.1% (Figure 1). Comparisons between the sociodemographic characteristics (age, gender, nationality, place of residence, number of admissions to hospital) of the study sample and the general population of stroke victims showed no differences. Among the 94 patients (mean age 65.5 years), 32 had no designated caregiver (67.6 years) and 62 had a family caregiver (64.4 years) (Baumann 2012b).

Socio-economic and stroke-related characteristics

Two groups of 31 family caregivers (average age 59.3 years; on average, 5 years younger than the patients they cared for) were obtained. More family caregivers with a LS ≤7 cared for stroke patients affected by neurological impairment of motor abilities (66% vs. 28%, including speech and swallowing, muscle power and tone, reflexes, balance, gait, coordination and apraxia), sensory deficits (69% vs. 41%, including loss of primary sensations or perception, numbness, tingling or altered sensitivity) and memory-related residual disability (55% vs. 28%) (Table 1).

The experience of caregiving

No significant difference was found between the various aspects of the caregiver esteem dimension. However, fewer family caregivers with a LS ≤7 reported that their "family works together at caring." More found that caregiving affected their schedule; they felt "tired all the time" and were exhausted of physical strength owing to caregiving tasks (Table 2).

The family and couple relationships

A great majority of the family caregivers with a LS ≤7 reported that stroke "entails serious upheaval in [their] family," but for 3/5, "social life goes on as before." Among the spouses (25 respondents with a LS ≤7 vs. 27), a majority of those with a LS ≤7 recognized that stroke was "a drama" that caused "serious upheaval in [their] couple relationship" which meant "the end of plans for the future." For a quarter, stroke "often put a distance between [them] and [their] children." Most declared they "cannot leave the stroke-affected person alone for too long" and they now have more "household responsibilities" (Table 3).

Discussion

Our study aimed to explain why the caregiving role, in home-based post-stroke caring with its familial, social and emotional repercussions, constitutes a lifestyle with a health risk. In our findings, more family caregivers with low life satisfaction, living at home with stroke survivors, cared for patients affected by motor, sensory and memory impairments. For a great majority of family caregivers – in particular, spouses with low satisfaction – their experience of caregiving reflects a lifestyle that puts their health at risk.

TABLE 2. The experience of caregiving (%)

		Life satisfaction		
		LS ≤7	**LS >7**	***p***
Caregiver's esteem	I really want to care for him/her.	65.2	63.6	0.330
	I feel privileged to care for him/her.	87.0	95.2	1.000
	I enjoy caring for him/her.	65.2	90.5	0.113
	Caring for him/her makes me feel good.	65.2	71.4	0.325
	Caring for him/her is important to me.	87.0	90.5	0.609
	I will never be able to do enough caregiving to repay him/her (reversed).	34.8	47.6	0.556
Lack of family support	I resent having to care for him/her (reversed).	13.6	4.8	0.421
	It is very difficult to get help from my family in taking care of him/her.	21.7	0.0	0.081§
	Since caring for him/her, I feel my family has abandoned me.	13.0	0.0	0.103
	My family (brothers, sisters, children) left me alone to care for him/her.	45.5	23.8	0.402
	My family works together at caring for him/her (reversed).	34.8	71.4	0.007**
	Others have dumped caring for him/her onto me.	30.4	22.7	0.806
Impact on finances	It is difficult to pay for him/her.	8.7	4.8	0.288
	Financial resources are adequate (reversed).	78.3	71.4	0.247
	Caring for him/her puts a financial strain on me.	8.7	0.0	0.037*
Impact on schedule	I have to stop in the middle of my work or activities to provide care.	34.8	4.8	0.030*
	I have eliminated things from my schedule since caring for him/her.	47.8	9.5	0.021*
	My activities are centred around caring for him/her.	59.1	31.8	0.225
	I visit family and friends less since I have been caring for him/her.	54.5	14.3	0.021*
	The constant interruptions make it difficult to find time for relaxation.	39.1	9.5	0.074§
Impact on health	It takes all my physical strength to care for him/her.	73.9	71.4	0.092§
	I am healthy enough to care for him/her (reversed).	82.6	81.0	0.120
	My health has gotten worse since I've been caring for him/her.	23.8	4.8	0.257
	Since caring for him/her, it seems like I'm tired all the time.	56.5	14.3	0.013*

p Significance level (§ ≤0.1; * ≤0.05; ** ≤0.01).

Percentages indicate the proportions of respondents who "completely agree" or "agree."

Stroke patients with physical impairments require family caregiver support in their self-care (help with showering, dressing, taking transport, preparing food, managing the shopping) and with mobility (walking, managing stairs, bending down while unsteady on their feet, standing for any length of time). As a consequence, we observed in our findings that those family caregivers with low life satisfaction were more likely to perceive themselves as in a permanent state of fatigue and to feel that caregiving was taking all their physical strength. This constant fatigue may be attributable to the constant disruptions in their routine activities related to their caregiving role that make finding time for relaxation and social life difficult. Swedish law has recognized the repercussions on family caregivers in a 2009 amendment that calls for assistance in minimizing the caregiving burden (Bergstöm et al. 2011).

TABLE 3. Social and couple relationships (%)

		Life satisfaction		
		LS ≤7	**LS >7**	***p***
Family relationships	The stroke has brought serious upheaval to my family.	82.8	51.7	0.024*
	Some time after the stroke event, my family worked together in taking care of the stroke-affected person.	81.5	78.6	1.000
	The stroke has strengthened family bonds.	68.0	69.0	1.000
Social isolation	The bonds between us (relatives, friends) remained as they were before or are stronger.	75.9	93.1	0.144
	We have lost many friends.	10.3	10.3	1.000
	Social life goes on as before.	58.6	96.6	0.001***
	Now we are ashamed of seeing our friends.	6.9	0.0	0.491
Disruptions within the couple relationship	The stroke brought serious upheaval to us as a couple.	57.1	25.9	0.029*
	I have perceived the stroke as a drama that my couple relationship could not overcome.	54.2	7.4	0.000***
	The stroke has meant the end of plans for the future that we had as a couple.	45.8	11.1	0.011*
	When a couple's relationship is already conflictive, a stroke worsens it.	31.8	48.0	0.373
	A stroke brings changes to a couple's relationship.	45.8	34.6	0.565
	Stroke often puts a distance between our children and us.	23.1	0.0	0.010*
Distribution of roles within the couple	I am more in charge of the housekeeping, cooking and shopping.	24.0	4.0	0.111
	I take care of the administrative affairs now.	16.0	15.4	0.540
	I organize the holidays and the leisure time now.	8.7	4.2	0.040*
	I am more in charge of our relationships with professionals (health professionals, cleaning professionals, etc.).	33.3	36.8	1.000
	I have more household responsibilities.	38.1	10.5	0.069§
	The responsibilities are shared as before.	79.2	81.5	0.000
	I cannot leave the stroke-affected person alone for too long.	60.7	17.2	0.001**

p Significance level (§ ≤0.1; * ≤0.05; ** ≤0.01).

Percentages indicate the proportions of respondents who "completely agree" or "agree."

Neurological impairments in sensory and memory-related functions can change survivors' cognitive processes. Loss of cognition has more impact if the affected skill was central to pre-stroke self-defining activities; day-to-day required efforts to concentrate were perceived as a new source of frustration. Associated with memory loss, the survivor's ability to concentrate was reduced. At the same time, reduced memory led patients to lose their sense of context and time perspective, and resulted in a perception of being distanced from those around them, including family, community and social networks. For our family caregivers with the lowest level of life satisfaction, stroke entailed serious familial upheaval, a finding in line with earlier research on caregivers' reactions (Lucas et al. 2003; Ostwald et al. 2009). For some, their social lives went on as before, but others perceived a negative readjustment of their daily interpersonal relationships. This was particularly true of the caregivers who found it difficult to get family help. Lack of social support can generate fear about current and future functioning, and alter expectations of improvement. This finding reflects the psychological difficulties of caring for patients, in particular those with memory disorders (Baumann et al. 2011).

More family caregivers with a low level of life satisfaction eliminated engagements from their schedule and visited family and friends less. In other words, home-based caring is determined by the constant dependency of the stroke patient on his or her caregivers. The caregiving role creates a privileged relationship with the care recipient, but in some situations social isolation is one of the negative consequences. A decrease in leisure time, as demonstrated elsewhere, also affects how caregivers assess their lives as a whole (Cook et al. 2005). Moreover, impoverished relationships have been associated with low self-perceived LS in studies in the field (Carlsson et al. 2007). In such a situation, support from family and friends may increase in value. Following the acute phase, the caregiver's individual appraisal of both the personal consequences of the stroke and his or her coping capacity affects psychological well-being more than does the objective disability of the patient (Forsberg-Wärleby and Möller 2001).

Caregiver esteem shows that their caregiving-related daily activities made sense to them and that they appreciated caring for their relatives. However, the lifestyle and experience of caregiving depends on the cultural context in which it is carried out, as well as material life conditions. Particularly for family caregivers having a low satisfaction with life, caring produces strain because of their financial situation. In our sample, the majority of caregivers were retired. Despite the socio-economic differences between care settings and domestic assistance, stroke is a life-threatening and potentially disabling event, as well as an important family issue. On the one hand, difficulties are likely to intensify as the family reaches a situation of greater social vulnerability with the attendant health risks. On the other hand, social factors, particularly socio-economic status, play a large role in determining access to services (Braveman 2010).

For half of the spouse-caregivers with low satisfaction, the partner's stroke brought disturbances to their relationship; it was a "drama" that ended the couple's plans for the future. Self-confidence in a couple's stability may favour their emotional recovery from the upheavals of stroke and acceptance of the irreversible. Confidence increases the preparedness of the spouse to assume the caregiving role (Ostwald et al. 2009). Moreover, as caregivers accumulate day-by-day experience of healthcare tasks and their caregiving role, their perspective needs to be incorporated in guiding these interventions. Improving our understanding of these experiences, principally the repercussions on familial and couple relationships, social lives and plans for the future, can contribute to our ability to sustain home-based care for those stroke survivors willing to continue to live at home. Stroke distances some family caregivers with low life satisfaction from their children. Therefore, stroke onset must be considered not only as requiring an adaptation to changes in material conditions but also as a painful family experience involving emotional and relational adjustments.

Accordingly, spouses may assume new responsibilities that imply a reconfiguration of the relationship with the care recipient (Green and King 2007). Regarding changes in the distribution of duties, more spouses with low life satisfaction recognized that they could not leave the stroke-affected person alone for too long, or easily organize household responsibilities, holidays and leisure time. A fulfilling family and social environment helps provide the resources to readjust future plans to the present situation and increase confidence when assuming the caregiving role. Efforts to determine how the caregivers of stroke-affected people could be better supported and prepared by healthcare, social services and education professionals is a topical question that is directly relevant – or soon will be – to a large number of us. Interventions to enhance community-based rehabilitation should be designed on the basis of sound information (Oupra et al. 2010).

Limitations

Our protocol – follow-up 24 months after onset of cerebrovascular disease – remains rare because it is expensive and difficult to organize. Numerous survivors died, lived in institutions, changed their residence (e.g., moved in with an adult child) or failed to respond to our request for an interview. The estimated participation rate was small but similar to that of recent studies (27%) (Bergstöm et al. 2011). Our sample was built from volunteers who agreed to take part, but were identified after the patients gave their consent by a posted letter; this option reduced the response rate. Finally, the interviews took place at home, which may have discouraged some potential participants.

Finally, a self-rated life satisfaction indicator must be interpreted cautiously because an objective life situation is not always associated with a corresponding subjective judgment (Ferring et al. 2010). A life situation described with respect to objective standards may be good but subjectively evaluated as bad, or on the contrary, described by objectively bad conditions but subjectively judged as good.

Conclusion

The responsibilities of supporting and caring for stroke patients are often assumed by a single family caregiver. Adjusting to life at home, coping with dependencies and disabilities, and learning how to resume psychosocial roles is a complex process. In Canada, nearly half of caregivers of stroke patients are reportedly at risk for clinical depression and reduced involvement in social and occupational life, a finding that represents a cost both for families and for the healthcare system (Teasell et al. 2009). The Global Mental Health Action Plan produced a set of recommendations to prevent social suffering and psychic disorders, and promote well-being (WHO 2013). These recommendations are based on the same principles as the report of Hachinski and colleagues (2010), which proposes a multisectoral approach in professional practice and empowerment of patients and families.

Adapted to health, the theoretical foundation of the capability approach offers insights for developing family caregivers' well-being by means of both individual initiatives and a collective determination (Bucki et al. 2012). Successful home-based healthcare requires that family caregivers, along with stroke patients, find new ways of solving problems, communicating and dealing emotionally with others. Managing this situation involves one specific rearticulation of the different risk dimensions centred on strategy integrating such concepts as lifestyle at risk (Massé 2007). An approach based on the analysis of lifestyles would enable a better accounting of behaviours, social contexts and structural constraints (social inequalities, differing social reports).

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