

# Increased Residual Disability Among Poststroke Survivors and the Repercussions for the Lives of Informal Caregivers

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**Purpose:** To analyze the associations between increased residual disability among poststroke survivors and the repercussions for their informal caregivers' lives, taking into account the latter's gender and education level. **Methods:** 215 stroke survivors (64.5 years; 55.8% men) were recruited by one neurologist from each of the 22 French regions. Katz Index of Independence in Activities of Daily Living (Katz ADL) was mean 9.3, and 54% still had impairments in "more than two of the six neurological domains" of the American Heart Association Stroke Outcome Classification (AHA.SOC): motor, sensory, vision, affect, cognition, and language. The 215 caregivers (57.8 years; 72.1% women) completed a face-to-face questionnaire concerning their social (8 items), material (4 items), and emotional (8 items) repercussions. **Results:** Katz ADL and AHA.SOC were significantly related to social repercussions for caregivers. Lack of autonomy among stroke survivors (low Katz ADL) was associated with the material difficulties of most concern to caregivers: "I needed to move house" (odds ratio [OR] 1.16; 95% CI, 1.07-1.27) and "I cannot go out anymore" (OR 1.29; 95% CI, 1.16-1.44). Being a male caregiver was strongly associated with a feeling of injustice (OR 2.53; 95% CI, 1.07-6.00). A low educational level was linked to an increased feeling of fear (OR 2.61; 95% CI, 1.05-6.51) and a greater feeling of isolation (OR 6.49; 95% CI, 1.20-35.02). **Conclusion:** Increased dependency post stroke leads to impoverishment in the caregiver's social relationships. Evaluating the emotional repercussions, particularly for men, is an important aspect of enabling survivors to continue to live at home. Innovative accompaniment and counseling services should be considered. **Key words:** cardiovascular accident, caregivers, gender, level education, repercussions, stroke

Stroke is the third most frequent cause of death and the main cause of serious, long-term disability in postindustrialized and developing nations.<sup>1-3</sup> Its relevance to society is reflected not only in its high prevalence, but also in the long-term disability that survivors often experience and in its substantial socioeconomic effects on daily life. Stroke is also considered as a traumatic event that heightens relationships within couples<sup>4-6</sup> and between members of the extended family,<sup>7</sup> leading in most cases to a deterioration in the relationship with the stroke survivor.

The length of costly long-term inpatient rehabilitation is decreasing, with a change of focus toward community-based rehabilitation.<sup>8</sup> During the inpatient period, caregivers mainly request illness-related information and rarely ask for psychological advice. However, during outpatient rehabilitation, the demand for further information decreases and the expectation of emotional assistance increasingly comes to the fore as this new situation often damages informal caregivers' health

and impairs the well-being of the family.<sup>9</sup> In France, no specific counselling services are available after the discharge from inpatient rehabilitation.

Stroke predominantly exerts negative effects on the quality of life of unpaid male and female caregivers<sup>10</sup>: it lessens their scope for mobility, self-care, communication, and leisure activity and can lead to cognitive impairments, depression, and personality changes.<sup>6,7,11-17</sup> The lingering sequelae of stroke may be harmful to a couple's relationship because of changes in intimacy and sexuality.<sup>5,6</sup> Men and women often go through emotional disturbances due to long-term caregiving.<sup>18</sup> A way to help overcome these stroke-related negative consequences and enable stroke survivors to live at home is to provide patients and their families with appropriate information on risk-factor reduction

and positive coping strategies to prevent future stroke<sup>12</sup> and to actively encourage them to adopt a healthy lifestyle.<sup>13,15,19</sup> Caregiving involves several aspects of human behavior.<sup>20</sup> Caregivers need not only information that will help them understand the changes that the stroke onset has brought in their family life, but also access to professional advice on how to handle the experience of caregiving.<sup>18,21</sup>

A wide range of literature on caregiving has focused on the “gendered styles of care,”<sup>22</sup> claiming that caregivers act and react differently according to their gender identity, regardless of their relationship to the recipient.<sup>19,23</sup> Male caregiving is generally described as managerial and instrumental, while female caregiving is seen as intimately connected with the maintenance of family relationships.<sup>22</sup> According to this viewpoint, the stroke onset brings a series of readjustment processes within the couple concerning the family roles each member used to assume.<sup>16</sup> The way couples undertake these adaptation processes is influenced by the attitudes of each spouse and by the dominant societal values.<sup>24</sup> Moreover, as family adaptation processes continue through the chronic illness evolution, the needs that caregivers of stroke survivors have for professional assistance may change over the course of rehabilitation and will feature gender- and age-specific differences. However, this gender- and age-specific differential is controversial; for example, research conducted in Germany found that women asked for professional assistance much more often than did men,<sup>9</sup> whereas a study in Japan reported the reverse.<sup>25</sup>

At 1 year after the stroke event (the minimum period of time since the stroke onset required for participation in our research), stroke survivors have generally been discharged home from the hospital. By then, stroke-related alterations within their social relationships and their family’s economic and professional situation have more or less stabilized. As the informal caregivers’ needs vary according to the particular recipient-giver relationship, this study aims to analyze the relationship between increased residual disability among post stroke survivors and the social, material, and emotional repercussions for their informal caregivers’ lives, taking into account the gender and education level of the caregivers.

## Methods

### Population of poststroke survivors

This study is part of a wider national descriptive survey of survivors undertaken in France among the general population aged over 18 years who suffered a stroke at least 1 year previously.<sup>26</sup> Using the French network of the Catherine Delannoy Private Institute (CDPI), one neurologist in the principal town of each of 22 French regions invited the first 10 patients who came to purchase medication for their stroke. The CDPI investigator research practitioner obtained 215 post stroke survivor participants who were receiving care, living at home, and willing to give written consent (inclusion criteria). Poststroke survivors were excluded if they were dependent on a caregiver before the stroke, lived in a residential home, or had a terminal or psychiatric illness that, in the researcher’s judgment, made their participation in this study inappropriate.

### Study design and measures of poststroke survivors’ level of autonomy

Using face-to-face structured interviews, the CDPI investigator practitioner collected data covering sociodemographic characteristics and information on residual disability after the stroke, which was measured with the following 2 tools.

The American Heart Association Stroke Outcome Classification (AHA.SOC) is a validated system that documents stroke-related neurological impairments and disabilities in a single summary score covering 6 domains: motor, sensory, vision, affect, cognition, and language.<sup>27</sup> The number of deficiency domains affected was regrouped in 3 categories: 1 domain impaired, 2 domains impaired, and more than 2 domains impaired.

The Katz Index of Independence in Activities of Daily Living (ADL), commonly referred to as the Katz ADL, assesses functional status in terms of the stroke survivor’s ability to independently carry out daily life activities. This index scores adequacy of performance in 6 functions (bathing, dressing, toileting, transferring, continence, and feeding) from A (*independent in all items*) to G (*completely dependent*).<sup>28</sup>

### Population of informal caregivers

The 215 post stroke survivors were asked to identify their main caregiver, who was then asked to voluntarily evaluate the consequences of his/her caring role. The informal caregiver was defined as “the person who had the main responsibility for everyday activity of the post stroke survivor.” He/she could be a spouse, a son, a daughter, or a friend but not a nursing home staff member. Specifically trained professional interviewers from a polling company interviewed the caregivers (all of whom had given their consent to take part in the study), meeting them in the caregivers’ homes.

### Study design and measures of repercussions for caregivers

Using face-to-face structured interviews, male and female research nurses collected data covering sociodemographic characteristics and information on the social, material, and emotional repercussions for the caregivers’ lives. Two groups of data were collected by a cross-sectional survey, applying a quantitative research approach.

Sociodemographic characteristics recorded were gender, occupational status, relationship with the care recipient, and the type of help provided. Occupational status was classified as “nonmanual,” “manual,” or “unemployed” and educational level as “primary education” (less than 8 years of education), “some secondary education” (from 9 to 11 years), and “completed secondary education” (more than 12 years including college or university level).

Items representing the stroke-related repercussions for the caregivers’ lives were elaborated after having carried out an exploratory qualitative pilot study (phase 1) with 10 stroke survivor-caregiver pairs.<sup>4</sup> Items for the questionnaire using this survey (phase 2) were built, tested, and classified by experts. They concerned social (8 items), material (4 items), and emotional (8 items) repercussions for the caregivers (see **Table 3**). The level of agreement regarding the list of proposed assertions was assessed according to 4 possible responses: “completely agree,” “broadly agree,” “broadly disagree,” and “completely disagree.”

### Ethical aspects

Informed consent was obtained before each interview, and the study protocol was approved by the French National Committee for the Protection of Confidential Information at the *Commission Nationale de l’Informatique et des Libertés*. Poststroke survivors and caregivers were visited at home and received financial compensation for their time. This is a common practice in research in France, widely used by the CDPI. It enables contact to be made with patients who are not followed by hospitals, and it facilitates interviews carried out in the interviewee’s home.

### Statistical analysis

Quantitative outcome variables were compared using Student *t* test and the Mann-Whitney test, and categorical variables were compared using the chi-square test or Fisher exact tests. Two-tailed tests were applied with a significance threshold of 0.05. Responses to repercussions items were classified as “agree” (completely agree and broadly agree) or “disagree” (broadly disagree and completely disagree). Two models of multiple logistic regression were then adjusted for each of these items in order to estimate (a) the effects of the stroke survivor’s functional status (Katz-ADL) and the number of neurological deficiency domains (AHA.SOC), adjusted for the age and the gender of the stroke survivor and the age, gender, educational level, and professional activity of the caregiver; and (b) the effects of the caregiver’s gender and educational level, adjusted for the stroke survivor’s age, gender, number of neurological deficiencies, and functional status, and the caregiver’s age and professional activity. The multiple logistic regression model was used to estimate the effects of those factors on the probability of caregiver interviewees agreeing with each of the repercussions sentences, by adjusting for the likely confounding factors. The level of statistical significance used in the whole analysis was  $P \leq .05$ .

## Results

### Poststroke survivors’ characteristics

There were 215 poststroke survivors (mean age 64.5 years; range, 21 to 98 years), 55.8% of them

**Table 1.** Poststroke survivors' characteristics

Characteristics	Patients (n=215)	
	n	%
Gender		
Female	95	44.2
Male	120	55.8
Mean age (SD)		
Female	64 (14.7)	
Male	64.8 (13.6)	
Time since stroke, years		
1-5	117	54.4
6-10	63	29.3
>10	35	16.3
Neurological deficiency (AHA.SOC domains)		
1 domain impaired	49	22.8
2 domains impaired	50	23.2
More than 2 domains	116	54
Mean Katz ADL score (SD)		
Female	9.7 (4.3)	
Male	9 (3.9)	

Note: AHA.SOC = American Heart Association Stroke Outcome Classification; Katz ADL = Katz Index of Independence in Activities of Daily Living.

were men, who volunteered to participate in this survey (**Table 1**). The time after the stroke was 1 to 5 years in 54.4% of the interviewees. More than half of the survivors (54%) remained impaired in more than 2 AHA.SOC domains. The mean reported disability, as measured by the Katz ADL, was 9.3 (median 7; range, 6 to 18).

### Caregivers' characteristics

The 215 informal main caregivers (mean age, 57.8 years; range, 21 to 98 years) were, on average, 7 years younger than the poststroke survivors; 43% of them were aged 65 years or more (**Table 2**). The majority were women (72.1%) and 93% were members of the poststroke survivor's family: 67.9% were the spouse, and 19.5% were a son or daughter. Among the whole population of participants, 66.5% had completed at least 9 years of education.

### Relationship between the survivors' status and impairment and the repercussions for the caregivers

Number of neurological domains impaired and the poststroke survivors' ability to independently perform ADLs strongly determined the social

**Table 2.** Main informal caregiver characteristics

Characteristics	Caregivers (n = 215)	
	n	%
Gender		
Female	155	72.1
Male	60	27.9
Mean age (SD)		
Female	57.8 (14.2)	
Male	57.9 (13.2)	
Caregiver relationship with stroke survivor		
Wife/husband	146	67.9
Son/daughter	42	19.5
Sibling	6	2.8
Parent	6	2.8
Other	15	7.0
Education level		
Primary education (8 years or less)	72	33.5
Some secondary education (9–11 years)	55	25.6
Completed secondary education (12 years or more)	88	40.9
Occupational activity		
Nonmanual	58	27
Manual	62	28.8
Not working	95	44.2

consequences of the care provided by the caregivers (**Table 3**). Increased dependency and an increased number of domains of dependency (AHA.SOC) were positively associated with the informal caregivers' perception of facing increasing and nearly unbearable social problems. However, less predictably, most values of adjusted odd ratio (OR) for social repercussion items increased when neurological impairment rose from 1 impaired domain to 2 impaired domains and more than 2 impaired domains, showing that the aspect that informal caregivers found hardest to bear was the decline in the mental health of their stroke-survivor relative. A low level of autonomy (Katz ADL) of the survivor was associated with the material difficulties that tended to be of principal concern for the caregivers: "I needed to move house" (OR 1.16; 95% CI, 1.07-1.27) and "I cannot go out any more" (OR 1.29; 95% CI, 1.16-1.44).

### Relationship between the educational level and gender of caregivers and the repercussions on their lives

Caregivers' educational level and gender were significant determinants of the emotional impact

**Table 3.** Effects of poststroke survivors' functional status and number of neurological deficiency domains on the repercussions for the informal caregivers' life [adjusted odds ratio and 95 % confidence interval (CI)\*]

Repercussions	Katz ADL	No. of neurological domains impaired (AHA.SOC)	
		2 domains / 1 domain	More than 2 domains / 1 domain
<b>Social</b>			
The stroke caused considerable repercussion in my family	1.16 (1.06-1.27)	NS	2.19 (1.02-4.72)
The stroke weakened family contacts	NS	NS	NS
The stroke is often a cause of distance problems with the children	1.15 (1.04-1.27)	NS	4.66 (1.34-16.1)
We had few demonstrations of sympathy	NS	NS	NS
We lost many friends	1.16 (1.06-1.28)	NS	3.22 (1.22-8.50)
Social life is not as it was	1.20 (1.10-1.32)	NS	3.07 (1.18-8.00)
Friends are bothered	1.16 (1.06-1.28)	3.36 (1.15-9.81)	4.15 (1.58-10.91)
It takes time to do simple things	1.18 (1.06-1.31)	NS	3.12 (1.43-6.81)
<b>Material</b>			
I needed to move house	1.16 (1.07-1.27)	NS	NS
I cannot go out anymore	1.29 (1.16-1.44)	NS	NS
I have difficulty with access to the house	NS	3.21 (1.29-7.99)	NS
I had to modify my professional activity	NS	NS	NS
<b>Emotional</b>			
Abandonment (rejection) by others	1.17 (1.05-1.31)	NS	NS
Anxiety	NS	NS	NS
Weakness	NS	NS	NS
Injustice	NS	NS	3.16 (1.30-7.67)
Deep isolation	1.37 (1.17-1.61)	NS	NS
Fear	NS	NS	NS
Regression	NS	NS	NS
Depression	NS	NS	NS

Note: All values given as adjusted odds ratio (95% CI). Variables for adjustment were gender and age of survivors and gender, age, education level, and occupational activity of caregivers. NS = nonsignificant.

of caring (**Table 4**). Being a male caregiver was strongly associated with a feeling of injustice (OR 2.53; 95% CI, 1.07-6.00). A low educational level was linked to increased feelings of fear (OR 2.61; 95% CI, 1.05-6.51), and a higher level of feelings of isolation (OR 6.49; 95% CI, 1.20-35.02). Caregivers' gender had no apparent effect on the material impact, after adjustment for their care recipients' characteristics. The degree of autonomy of the stroke survivors was a better indicator. Moreover, the data did not support any association between the caregivers' educational level and the material and social difficulties arising from care-related work.

## Discussion

Functional status and stroke-related neurological impairment affected informal caregivers' material conditions and emotional well-being. Both were determinants of increased social problems. Stroke causes disability in ADL, cognitive alteration, and behavioral disturbance, all of which increase the informal caregiving workload.<sup>29-31</sup> It should be noted, however, that the survey sample included many poststroke survivors whose functional status was not severely limited. Katz ADL scores were low, reflecting minor stroke. However, people who were affected by a minor stroke and had no functional

**Table 4.** Variations of the repercussions on informal caregivers' lives according to their gender and educational level

Repercussions	Gender (F/M)	Educational level	
		9–11 years/8 years or less	12 years or more/8 years or less
<b>Social</b>			
The stroke caused considerable disruption in my family	NS	NS	NS
The stroke weakened family contacts	NS	NS	NS
The stroke is often a cause of problems with the children	NS	0.29 (0.10-0.85)	NS
We had few demonstrations of sympathy	NS	NS	NS
We lost many friends	NS	NS	NS
Social life is not as it was	NS	NS	NS
Friends are bothered	NS	0.34 (0.14-0.83)	NS
It takes time to do simple things	NS	NS	NS
<b>Material</b>			
I needed to move house	NS	NS	NS
I am unable to go out anymore	NS	0.40 (0.17-0.96)	NS
I have difficulty with access to the house	NS	NS	NS
I had to modify my professional activity	NS	NS	NS
<b>Emotional</b>			
Abandonment (rejection) by others	NS	NS	NS
Anxiety	0.39 (0.17-0.88)	NS	NS
Weakness	NS	NS	NS
Injustice	2.53 (1.07-6.00)	NS	NS
Deep isolation	NS	NS	6.49 (1.20-35.02)
Fear	NS	NS	2.61 (1.05-6.51)
Regression	NS	NS	NS
Depression	NS	NS	NS

Note: All values given as adjusted odds ratio (95% CI). Variables for adjustment were gender, age, number of neurological deficiency domains (American Heart Association Stroke Outcome Classification [AHA.SOC]) and Katz Index of Independence in Activities of Daily Living (Katz ADL) score of survivors and age and occupational activity of caregivers. NS = nonsignificant.

physical impairments still experienced less visible disabilities such as mental fatigue, emotional alterations, and difficulties with concentration and memory,<sup>32</sup> which were considered by their caregivers to be a major impediment to continuing with the lifestyle and maintaining the material life conditions they were used to.

The caregivers surveyed knew what to expect in relation to their recipients' behavior, mood, and functional ability. In line with previous research,<sup>20</sup> caregivers understood the requirements of caring and were able to calculate and estimate the impact of a progressive deterioration of their health and autonomy, making them react with anxiety to changes in the recipients' condition or events beyond their control. Poststroke survivors and their caregivers may have been very concerned about the risk of another, possibly more devastating, stroke event.

As regards the different experience of caregiving between men and women, in our study women reported difficulty with physically demanding care provision tasks, whereas men described a sense of social injustice. This may be explained by the emphasis men gave to the stroke-related repercussions on their lifestyle.<sup>32</sup> Compared to men, more caregiving women were unemployed and considered caregiving their main activity; they also tended to carry out more intensive and complex caring tasks, as stated in previous studies.<sup>19,25</sup> Among the informal caregivers who also had jobs, women reported greater difficulties than men in balancing care work with those responsibilities, to the point that relationships between family members were affected<sup>7</sup> and they had to make important changes in their occupational activity.<sup>6,19,33</sup> In interpreting these data, it should be considered that 1 year after

stroke, informal caregivers often cross a transitional phase of psychological difficulties. As stated in a previous study,<sup>4</sup> the most serious problem for caregivers, who commonly suffer from anxiety and depression, is the overwhelming responsibility related to the role taken within the family.

The responsibility increases as the emotional involvement of the caregiver rises; our findings highlighted that subjective psychosocial well-being is more at risk among men, as women seem to more likely accept having to make personal sacrifices.<sup>18</sup> Hypothetically, this difference may be attributable to a gendered socialization regarding the sexual division of domestic care work that would prepare men less well than women to cope emotionally with the upheavals of a stroke and to build up more efficient relationships with health professionals. Here, we also have to consider the coverage, accessibility, and availability of institutional support provided at outpatient early rehabilitation. Caregiving could be seen as a means of performing gender,<sup>22</sup> namely, caregivers' beliefs and behavior would be strategies for negotiating a social setting or as tools for constructing gender relations.<sup>16,18,34</sup> Such an understanding of caregiving brings in the need to consider generational changes and to apply a socioculturally sensitive approach.<sup>9,22</sup> Individuals' social, cultural, and economic environments influence adaptation to disability<sup>24</sup>; but here we also have to consider the structural arrangements societies make to improve the lives of people suffering from disabling chronic illness and of their informal caregivers.

#### Limitations and strengths of the study

As the sample did not include the complete spectrum of poststroke survivors living at home, respondents were not representative of the overall population of stroke-affected users of the French health system. The study population comprised poststroke survivors who agreed to be interviewed by a researcher at their own home and their main informal caregivers. The method used thus entails limitations relating to the voluntary nature of recruitment, to data collection via questionnaires administered in face-to-face interview at home, and to the subjectivity of individual responses. Second, the questionnaire

may not have captured the full extent of potential influences on the caregivers' lives, including those exerted by medical care and the support provided by community care professionals. Last, poststroke survivors were recruited according to a certified medical diagnosis, but we relied on caregivers' assessments of functional status, rather than clinical reports, which may differ.

Finally, the survey data analysis did not identify any association between the caregivers' material situation after stroke and their educational level. It may support Baumann and Aïach's conclusion that a caregiver's educational level does not influence the perception of the repercussions of chronic illness on the material life conditions or access to social support.<sup>35</sup> If we consider gender and educational level to be determinants of social inequality in health, we cannot fail to be astonished by the absence of more links between them and the repercussions of the stroke event on family and social life. Further research is needed. We support the contention that making the most of this kind of quantitative research-based information requires triangulation with qualitative research methods.

#### Practical implications to improve poststroke care after discharge from inpatient rehabilitation

Our study suggests that assessment of physical dependence and neurological impairment is a simplistic way of targeting intervention for caregivers. Some caregivers perceive themselves as being under considerable pressure to provide a high level of care with little support from professionals,<sup>36,37</sup> and the performance of gender is an important determinant of both perception and coping resources.<sup>22</sup> Long-term medical care for stroke survivors should therefore include early identification of caregivers at risk of adverse health effects. Individual levels of subjective burden should be taken into consideration, along with objective measures of stroke-related burden, and social repercussions for the caregivers' life quality.<sup>17,38-40</sup>

An important role for health care professionals is to help informal caregivers make the most of their skills, assist them in the transition from hospital to home, and provide support tailored to the family as they adapt to their new role. In

planning outpatient care, our findings lead us to strongly endorse the recommendation that program planners, policy makers, and professional care providers must act together to provide accessible, affordable, and innovative family-based support services and programs.<sup>19, 31</sup> Although this point was well made a decade ago,<sup>15</sup> it has yet to be acted upon in France. It is worth highlighting that Section VI of the French Public Health Code recognizes accompaniment as part of therapeutic education. Adjusting health promotion initiatives and professional counselling to the families' needs would help reduce current and future caregiving-related strains<sup>12</sup> and strengthen emotional links within the family support network.<sup>39</sup> When caregivers receive effective support (for instance, from a Web-based support group), the stroke event may also foster closer family ties and facilitate "being there" for one another.<sup>16</sup>

In designing professional assistance and offering it to caregivers, the performance of gender should be taken into account, as should medium- and long-term variations in the need for assistance.<sup>14</sup> Several measures have already been taken to offer assistance better matched to caregivers' needs. However, our data analysis suggests the need to introduce a more couple-based and subjective approach to more efficiently grasp the concrete life conditions and experiences of stroke-related changes of each recipient and caregiver pair,<sup>21, 37</sup> most of whom are couples.<sup>5, 17</sup> Hence, intervention policy designers should not generalize the experience of one subgroup (eg, women) to inform appropriate strategies for the whole population concerned,<sup>22</sup> but should take account of changes in needs and priorities over time<sup>40</sup> and across generations, using a situational family approach.

## Conclusion

The outcomes of this study provide new information about the difficulties encountered by caregivers 1 year or more after the stroke event. They shed light on the influence that a gender division of the work of caring has on the main informal caregivers' well-being and on their perception of the difficulties entailed by the provision of care and suggest that caregiving must be better understood as a means of performing

gender, the form and content of which is changing across generations.

These findings open up some new perspectives and suggest areas for improvement in family care practice and in professional health provision. They support the recommendation that program planners and policy makers should implement a family-based situational approach to provide services that will (a) help informal caregivers lessen the emotional pressures that long-term intensive care work entails, and (b) help caregivers (particularly men) deal more efficiently with physical, cognitive, and behavioral alterations in the care-recipient and manage rearrangements within the family. Interventions to reduce the impact of the perception of social injustice that seems to affect predominantly male caregivers<sup>33</sup> and to provide positive coping strategies enabling stroke survivors and their caregivers to increase their perceived control over daily life<sup>41</sup> will, with the provision of accessible programs, benefit not only stroke survivors, but also the whole family.<sup>7</sup> This addresses the objectives for 2015 of the Helsingborg Declaration on European Stroke Strategies.<sup>42</sup>

Further quantitative and qualitative research is required to examine the negative and positive effects of caring for stroke survivors, to better identify and analyze the changing needs of caregivers, and to assess the effectiveness of health services and community interventions in improving their quality of life.<sup>12</sup> New models for outpatient care must be designed to address these issues when tackling the lingering sequels of stroke. Evaluation of the negative physical and psychological effects on caregivers' health and quality of life is an important aspect of enabling stroke survivors to continue to live at home.<sup>17, 43</sup> Innovative accompaniment and counselling services should be considered to prepare families for the full extent of caregiving responsibilities by giving more attention to the relationship with the stroke survivor's partner, family life, and the maintenance of a support network.<sup>44</sup>

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