

ORIGINAL REPORT

PARTICIPATION AFTER STROKE: COMPARING PROXIES' AND PATIENTS' PERCEPTIONS

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Objective: This study aimed: (i) to determine the level of agreement between responses of people with stroke and their proxies on a participation questionnaire, and (ii) to explore patient and proxy characteristics related to disagreement between their responses.

Design: Cross-sectional study.

Subjects: A total of 40 community-dwelling people with stroke and their proxies (total $n = 80$).

Methods: Participants were evaluated separately in face-to-face interviews using the Assessment of Life Habits questionnaire (LIFE-H 3.1), which documents participation in daily activities and social roles. Sociodemographic and clinical variables, such as severity of motor impairment and cognitive functions, were also collected.

Results: Moderate to excellent agreement was found for the LIFE-H total score (intraclass correlation coefficient (ICC): 0.82), daily activities (ICC: 0.87) and social roles (ICC: 0.73) sub-scores. Proxies perceived more disruptions in participation than patients in several life domains ($p = 0.035–0.001$), but the differences between their scores were generally not clinically meaningful. Severity of motor disabilities was the best predictor of disagreement between patients and proxies.

Conclusion: These acceptable levels of agreement support the use of proxy responses to estimate the participation of people unable to respond themselves. However, some characteristics contributing to disagreement between respondents, such as severity of motor disabilities, should be considered when interpreting proxy information.

Key words: participation, outcome assessment (health care), proxy, observer variation, cerebrovascular accident.

J Rehabil Med 2008; 40: 28–35

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Submitted March 5, 2007; accepted May 24, 2007.

INTRODUCTION

Community-dwelling stroke survivors are likely to experience difficulties in accomplishing daily activities and, even more, may have to deal with disruptions in participation in their social roles, despite good functional recovery following rehabilitation (1). The use of a social participation measure covering

all aspects of daily activities and social roles may therefore be useful in comprehensively evaluating their functioning in the community and helping to determine the health and social services they might require. Since participation is an individual experience, it should be assessed with questionnaires focusing on the person's perceptions (2).

In the Disability Creation Process (DCP) model (3), the concept of participation is operationalized by the Assessment of Life Habits (LIFE-H) questionnaire (4). "Life habits" are defined as "daily activities and social roles that ensure the development and survival of the person in society throughout his or her life" (3). These activities are performed as part of the person's usual life and are therefore different from "standardized activities" as described in the International Classification of Functioning, Disability and Health (ICF) (5). Optimal social participation corresponds to the full accomplishment of life habits, resulting from the interaction between personal factors (such as the individual's organic system, aptitudes, age and gender) and environmental factors (physical and social) (3). This definition of participation is consistent with the conception of the ICF model, which considers participation to be the person's involvement in a life situation (5).

The LIFE-H covers all 12 domains of life habits proposed by the DCP model, which have similarities to 7 of the 9 ICF domains. The first 6 domains of the LIFE-H relate to daily activities (such as personal care and mobility), while the others refer to social roles (e.g. interpersonal relationships and leisure). Like other participation measures, the LIFE-H may be self-administered or administered in an interview, the latter version being used more often with older adults having disabilities following health problems such as stroke. Some of these people, however, may be unable to answer themselves due to severe cognitive problems. They are therefore usually excluded from studies on participation, which reduces the generalizability of the results. Reliance on information from proxies, such as relatives or friends who know the other person well, might be an interesting alternative if there is good agreement between them and people with stroke for the assessment of participation.

A number of studies have examined the validity of proxy responses, as a substitute for persons with stroke, for the assessment of functional independence (6, 7), instrumental activities of daily living (IADL) (7–9), social functioning (10), health-related quality of life (7, 11–16), handicap (17), and

physical, cognitive and psychosocial consequences of stroke (18). These studies suggest that the level of agreement between stroke survivors and proxies may differ depending on the type of construct measured. Moderate to excellent agreement is generally reported for the assessment of more directly observable domains, including ADL (6, 7), IADL (7–9) and physical capabilities (11–16, 18). The level of agreement, however, decreases for measures of more subjective and less observable domains, such as pain (11, 13), leisure (7–9), psychosocial and cognitive functioning (6, 7, 10, 11, 13–16, 18), with low to good subject-proxy correlations. For the assessment of social participation, more specifically, Duncan et al. (18) reported moderate agreement between patients' and proxies' mean scores on 9 items of the Stroke Impact Scale (SIS) (intraclass correlation coefficient (ICC): 0.56). Also, Cusick et al. (17) compared the responses of persons with various disabilities (including people with stroke) with those of their proxies on the Craig Handicap Assessment and Reporting Technique (CHART), which assesses a concept related to social participation. The results for the sample of patients with stroke indicated good to excellent agreement for the CHART total score (ICC: 0.79) and the 6 subscales (ICC range: 0.74–0.83). Finally, when responses differed between the 2 groups of respondents, proxies tended to describe more problems than did the people with stroke (8, 11, 14–16, 18).

Many factors might reduce the level of agreement between patients' and proxies' assessments. The severity of impairments following a stroke might increase response discrepancy in patient-proxy dyads (14, 18). Tooth and colleagues (8) also found evidence of a scoring bias associated with patient and proxy sociodemographic characteristics. In their study, spouses and female proxies scored patients lower on domestic activities, while men and younger people who had had a stroke scored themselves higher on outdoor activities in comparison with proxies' perceptions. Other studies carried out with older adults having disabilities, but not specifically due to stroke, also indicated that some characteristics of older subjects and proxies, as well as the context of their relationship, might affect the level of agreement between their respective responses (19–22). Among other findings, researchers reported that living together (21, 23, 24) and a close family relationship (19, 21, 25, 26) appear to increase agreement while higher caregiver burden (15, 20, 22, 27, 28) and depressive symptoms in patients (21, 29) are factors potentially contributing to differences between raters. However, these findings are not consistent across studies. There is a real need for additional research concerning the use of proxy assessments to fully understand the possibilities and limitations of this type of information, and also to clarify factors that may influence agreement between people with stroke and proxies across different constructs. Further examination of the validity of using proxy information to estimate social participation, which is increasingly considered a pivotal outcome of rehabilitation after stroke, seems particularly relevant.

The purpose of this study was therefore to verify the validity of proxy responses assessing participation of people who

had had a stroke. More specifically, the study aimed: (i) to determine the level of agreement between responses of people who had had a stroke and their proxies on a participation questionnaire, and (ii) to explore patient and proxy characteristics related to disagreement between their responses.

METHODS

Participants

This study employed a cross-sectional design involving 2 groups of participants. The first group comprised 40 people aged 50 years or over, who had been clinically diagnosed as having had a stroke. To be included in this study, they also had to be able to communicate in French and to live in the community (own home or private seniors' residence) in the region of Sherbrooke, Québec, Canada. Excluded were people who were unable to give their consent, and who had moderate to severe cognitive deficits (score on the Mini-Mental State Examination (MMSE) under the 5th percentile for age and schooling (30)) or serious communication problems (moderate to severe aphasia based on clinical judgment). The study participants included patients who had been hospitalized for stroke in the last 2 years in the inpatient rehabilitation unit of the University Institute of Geriatrics of Sherbrooke (UIGS) and subjects who had participated in a previous study at the Research Centre on Aging of the UIGS (convenience sample).

Each eligible person with stroke who agreed to participate was asked to identify a primary support person, such as a spouse, son, daughter, other family member or friend, who was then recruited to be part of the second group of subjects. Eligible proxies were those who were aged 18 years or over, had known the other participant for at least one year and saw him/her at least once a week. They were also required to have sufficient cognitive ability to participate in the assessment (clinical judgment) and be able to communicate in French. Stroke survivors who could not identify a proxy on the basis of these criteria were not included in the study.

Data collection procedure

Participants were met in person at their home or at the Research Centre on Aging for final verification of the eligibility criteria, signature of the informed consent form and data collection. People with stroke and their proxies were assessed separately by the same occupational therapist with the measurement instruments described below. Proxy interviews were conducted within 7 days of the patient's assessment. One half of the proxies were interviewed first and the other half second. The research protocol was approved by the Research Ethics Committee of the UIGS.

Variables and measurement instruments

Participation. Participation was measured with the Assessment of Life Habits (short version 3.1) (LIFE-H 3.1) (4). This tool comprises 77 items covering the 12 domains of the DCP model (3). These domains include: nutrition, fitness, personal care, communication, housing, mobility, responsibilities, interpersonal relationships, community life, education, employment and leisure. In the present study, the "employment" and "education" domains were excluded because they are irrelevant for the majority of older adults with stroke, leaving a total of 67 items divided into 10 domains. Examples of the questionnaire's items in the various domains are provided in Appendix I.

The LIFE-H evaluates the level of participation in daily activities and social roles by considering both the *degree of difficulty* and the *type of assistance required* (technical assistance, physical arrangements, human help). A scale ranging from 0 to 9 was developed by combining these 2 concepts, where 0 indicates total handicap (meaning that the activity or social role is not accomplished) and 9 corresponds to optimal participation (meaning the activity or social role is performed without difficulty and without assistance). Continuous scores from 0 to 9 can be

generated for each domain, the 2 sub-scores (daily activities and social roles) and for the instrument as a whole (total score), by calculating the mean of applicable items. The reliability coefficients of the total score studied with older adults having disabilities are excellent (ICC and 95% confidence intervals (CI): 0.95 (0.91–0.98) for test-retest, and 0.89 (0.80–0.93) for inter-rater (31)). Another study supports the construct validity of the LIFE-H as a participation measure (32).

The LIFE-H was administered as an interview with both stroke survivors and proxies to ensure the questions were understood and to reduce missing data. The wording of the items was modified slightly in the proxy version, so that the questionnaire assessed the proxy's perception of the patient's participation.

Factors potentially influencing agreement

The stroke survivors' cognitive functions were screened with the MMSE (33), which was also used to verify their eligibility. The MMSE comprises 11 items and gives a maximum total score of 30. Stroke severity was estimated using the Physical Impairment Inventory (PII) of the Chedoke-McMaster Stroke Assessment (CMSA) (34). This tool evaluates the presence and severity of motor impairments of the arm, hand, leg and foot using a 7-point scale from 1 to 7, where 1 corresponds to the lowest level of motor recovery. The Geriatric Depression Scale (GDS) was used to estimate the presence and severity of depressive symptoms in both people with stroke and proxies (35). Scores on the GDS range from 0 to 30, with a score of 11 or more being indicative of depressive symptoms (36). Finally, the usual sociodemographic and clinical data were collected for both groups of participants. The context of the relationship between the people with stroke and their proxies (e.g. relationship of proxy, living together, time spent together, type of help provided by the proxy, frequency of help in ADL) was also documented.

Statistical analyses

The participants' characteristics are first described by means and standard deviations for the continuous variables and by frequency and percentage for the categorical variables. To determine the level of agreement between patients' and proxies' responses on the LIFE-H, ICCs and their 95% CIs were calculated for the total score, daily activities and social roles sub-scores, as well as the 10 life domains (objective 1). Guidelines used to interpret the different ICC values were as follows: ICC < 0.40: poor; 0.40 ≤ ICC < 0.75: fair to good; 0.75 ≤ ICC ≤ 1.00: excellent (37). Paired *t*-tests were also used to verify the presence of systematic differences between patients' and proxies' scores.

For the second objective, we first created *disagreement indexes* to appraise the amount of response discrepancy in each patient-proxy dyad on the assessment of social participation. The disagreement index represented the number of items for which there was a *difference greater than 1 point* between patient and proxy scores on the LIFE-H scale. Three disagreement indexes were calculated: an index for daily activities (ranging from 0 to 37 disagreements); another for social roles (ranging from 0 to 30) and a third for the total score (ranging from 0 to 67). Bivariate analyses were carried out to identify the independent variables (characteristics of patients and proxies, context of their relationship) associated with each disagreement index. Variables with a *p*-value under 0.10 were retained for the multiple regression analyses. The strategy used to select variables was the all-possible-regressions procedure, with the adjusted R² as the criterion for choosing the best model (38). A residual analysis was done to verify the basic assumptions.

RESULTS

Participants

Sociodemographic and clinical characteristics of the participants who had a stroke (*n* = 40) and their proxies (*n* = 40) are presented in Table I. The majority of participants with stroke

Table I. Sociodemographic and clinical characteristics of participants with stroke and proxies

	People with stroke <i>n</i> = 40	Proxies <i>n</i> = 40
Continuous variables (mean (SD))		
Age (years)	73.6 (8.4)	64.6 (13.7)
Schooling (years)	8.9 (3.4)	9.3 (3.7)
Number of months since stroke	43.5 (32.0)	–
Chedoke-McMaster Stroke Assessment		
Arm	4.9 (1.7)	–
Hand	4.5 (1.6)	–
Leg	4.6 (1.4)	–
Foot	4.3 (1.6)	–
Mini-Mental State Examination	26.7 (2.6)	–
Geriatric Depression Scale	10.1 (6.5)	5.9 (4.8)
Categorical variables (frequency (%))		
Sex		
Male	23 (57.5)	14 (35.0)
Female	17 (42.5)	26 (65.0)
Living environment		
Home	32 (80.0)	–
Seniors' private residence	8 (20.0)	–
Relationship of proxy		
Spouse	–	28 (70.0)
Other	–	12 (30.0)
Living with patient	–	30 (75.0)
Stroke type		
Ischemic	27 (67.5)	–
Hemorrhagic	5 (12.5)	–
Missing data	8 (20.0)	–
Side of motor impairment after stroke		
Right	21 (52.5)	–
Left	16 (40.0)	–
Bilateral	3 (7.5)	–
Previous stroke (yes)	11 (27.5)	–
Self-perceived health		
Excellent	1 (2.5)	13 (32.5)
Good	15 (37.5)	19 (47.5)
Fair	24 (60.0)	7 (17.5)
Poor	–	1 (2.5)

SD: standard deviation.

were male (57.5%) and lived at home (80%). For the most part, they had had their stroke more than one year before the assessment. CMSA mean scores indicate moderate motor impairments following stroke. Also, the people with stroke had no significant cognitive impairment, as indicated by the MMSE mean score. The proxy sample was predominantly women (65%) and spouses (70%), and the majority lived with the patient (75%).

Level of agreement between respondents (objective 1)

Patients' and proxies' scores on the LIFE-H are shown in Table II. Globally, the LIFE-H total score and 2 sub-scores (daily activities and social roles), calculated from both patients' and proxies' responses, suggest moderate disruptions in participation after stroke. The level of agreement between participants with stroke and proxies on the LIFE-H total score and 2 sub-scores ranges from good to excellent, with lower ICCs for the social roles sub-score. Moderate to excellent ICCs are also

Table II. Comparison of patients' and proxies' scores on the Assessment of Life Habits (LIFE-H)

LIFE-H (/9)	n	People with stroke Mean (SD)	Proxies Mean (SD)	Paired <i>t</i> -test (stroke-proxy) <i>p</i> -value	ICC Value (95% CI)
<i>Daily activities</i>					
Nutrition	40	6.8 (1.3)	6.4 (1.5)	0.020	0.76 (0.58–0.87)
Fitness	40	8.0 (0.9)	7.6 (1.1)	0.009	0.61 (0.35–0.78)
Personal care	40	7.1 (1.5)	7.0 (1.4)	0.457	0.93 (0.87–0.96)
Communication	40	7.7 (1.1)	7.6 (1.2)	0.455	0.59 (0.35–0.76)
Housing	40	5.9 (1.4)	5.5 (1.4)	0.001	0.83 (0.62–0.92)
Mobility	40	5.1 (2.3)	4.7 (2.5)	0.035	0.86 (0.74–0.93)
Sub-score	40	6.8 (1.2)	6.5 (1.2)	0.002	0.87 (0.70–0.93)
<i>Social roles</i>					
Responsibilities	40	7.0 (1.4)	6.7 (1.6)	0.110	0.63 (0.40–0.78)
Interpersonal relationships	39*	8.2 (1.0)	7.8 (1.3)	0.022	0.41 (0.12–0.64)
Community life	40	5.6 (2.4)	5.2 (2.6)	0.033	0.92 (0.84–0.96)
Leisure	20*	5.3 (2.9)	4.2 (3.0)	0.006	0.82 (0.47–0.93)
Sub-score	40	6.5 (1.5)	6.3 (1.6)	0.172	0.73 (0.54–0.85)
Total score	40	6.7 (1.2)	6.4 (1.3)	0.016	0.82 (0.67–0.90)

*Some participants were excluded because more than half of the items for this life domain did not apply to them.

n = number of pairs of respondents on the LIFE-H.

ICC: intraclass correlation coefficient; SD: standard deviation; CI: confidence interval.

observed for the assessment of the life domains apart from “Interpersonal relationships”, where patient-proxy agreement is only fair. In addition, proxies describe more disruptions in participation than do the patients in 7 of the 10 life domains assessed ($p = 0.035\text{--}0.001$).

Characteristics related to disagreement (objective 2)

Several characteristics of participants who had a stroke are related to disagreement between members of the dyads on the assessment of participation. Continuous variables and dichotomous variables associated with at least 1 of the 3 disagreement indexes with a p -value under 0.10 are shown in Tables III and IV, respectively. Several characteristics were *specifically* related to disagreement on the LIFE-H *daily activities* (i.e. self-perceived health, depressive symptoms, severity of arm impairment, sex and living environment) or on the *social roles* (i.e. number of months since stroke and cognitive functions), whereas *severity of lower extremity impairment* emerged as a factor increasing

disagreement on both daily activities and social roles. Proxy characteristics and variables related to the context of relationship were not associated with any of the disagreement indexes and were therefore not included in the regression models.

The results of the multiple regression analyses for each disagreement index (LIFE-H total score, daily activities and social roles sub-scores) are summarized in Table V. Severity of lower extremity impairment was the most important factor related to disagreement between patients and proxies on the LIFE-H total score, as well as daily activities and social roles sub-scores. For the LIFE-H total score, the presence of severe lower extremity impairment and poorer cognitive performance were found to predict greater disagreement and together explained 40% of the variance in disagreement indexes. In addition to the severity of lower extremity impairment and cognitive functions, number of months since stroke (greater number of months) was identified as a third predictor of disagreement in the assessment of participation in social roles. Thirty-two percent of the variance

Table III. Participants' characteristics related to disagreement (continuous variables*)

Independent variables	Disagreement on the LIFE-H (global instrument) <i>r</i> (<i>p</i> -value)	Disagreement on the LIFE-H daily activities <i>r</i> (<i>p</i> -value)	Disagreement on the LIFE-H social roles <i>r</i> (<i>p</i> -value)
Number of months since stroke	0.28 (0.093)	–	0.32 (0.053)
Patient CMSA score			
Arm	–0.27 (0.092)	–0.31 (0.052)	–
Leg	–0.50 (0.001)	–0.50 (0.001)	–0.36 (0.023)
Foot	–0.53 (0.001)	–0.48 (0.003)	–0.46 (0.004)
Patient MMSE score	–0.30 (0.056)	–	–0.31 (0.056)
Patient GDS score	–	0.34 (0.033)	–
Patient self-perceived health**	0.38 (0.015)	0.46 (0.003)	–

*Pearson correlation coefficients (r) were calculated. Correlations with a p -value higher than 0.10 are not shown.

**Scores range from 1 to 4. A lower score indicates better self-perceived health.

CMSA: Chedoke-McMaster Stroke Assessment; MMSE: Mini-Mental State Examination; GDS: Geriatric Depression Scale; LIFE-H: Assessment of Life Habits.

Table IV. Participants' characteristics related to disagreement (dichotomous variables*)

Independent variables	Disagreement on the LIFE-H (global instrument)		Disagreement on the LIFE-H daily activities		Disagreement on the LIFE-H social roles	
	Disagreement Index		Disagreement Index		Disagreement Index	
	Mean score (/ 67)	<i>p</i> -value	Mean score (/ 37)	<i>p</i> -value	Mean score (/ 30)	<i>p</i> -value
<i>Patient sex</i>						
Male	–	–	6.83	0.032	–	–
Female	–	–	9.65		–	–
<i>Patient living environment</i>						
Home	–	–	7.34	0.037	–	–
Seniors' private residence	–	–	10.75		–	–

**t*-tests were used because of the data normality of the dependent variable. Variables with a *p*-value higher than 0.10 are not shown. LIFE-H: Assessment of Life Habits.

Table V. Best models explaining disagreement between patients and proxies on the Assessment of Life Habits (LIFE-H) (using the all-possible-regressions procedure)

Disagreement on the LIFE-H (global instrument = 67 items)			
Variables included in the best regression model	Regression coefficient	<i>p</i> -value	<i>R</i> ²
Severity of lower extremity impairment (foot)	–2.30	<0.001	0.32
Cognitive functions	–0.72	0.049	0.40
Intercept	42.39	<0.001	–
Disagreement on the LIFE-H daily activities (37 items)			
Variables included in the best regression model	Regression coefficient	<i>p</i> -value	<i>R</i> ²
Severity of lower extremity impairment (leg)	–1.27	0.004	0.25
Living environment	3.24	0.020	0.37
Patient sex	–2.37	0.046	0.44
Intercept	14.57	<0.001	–
Disagreement on the LIFE-H social roles (30 items)			
Variables included in the best regression model	Regression coefficient	<i>p</i> -value	<i>R</i> ²
Severity of lower extremity impairment (foot)	–0.72	0.072	0.21
Cognitive functions	–0.42	0.056	0.27
Number of months since stroke	0.03	0.124	0.32
Intercept	18.54	0.003	–

was explained by these 3 clinical variables. Finally, in addition to the severity of lower extremity impairment, the best predictors of disagreement on the LIFE-H daily activities included 2 sociodemographic characteristics (patient sex (female) and patient living environment (seniors' private residence)), which together explained 44% of the variance.

DISCUSSION

The general objective of this study was to evaluate the validity of using proxies' responses to estimate social participation of people who had had a stroke. Moderate to excellent agreement between patients' and proxies' assessments was found on the LIFE-H total score, daily activities and social roles sub-scores, and the majority of the life domains. These acceptable levels of agreement suggest that proxies may provide valid information to assess social participation when people with stroke are unable to respond themselves because of cognitive impairment or other disabilities. These results also corroborate findings from other studies reporting similar levels of agreement for

the assessment of people who had a stroke with questionnaires such as the Stroke and Aphasia Quality of Life Scale-39 (16), the CHART (17) and the SIS (18).

Despite an overall satisfactory level of agreement on the LIFE-H, systematic differences were observed between patients' and proxies' scores for many life domains. As in previous research (8, 11, 14–16, 18), the study demonstrates that proxies generally report a lower level of participation in daily activities and social roles than do people with stroke. However, this difference does not appear clinically meaningful in most life domains, as other researchers also confirmed (14, 18). Only the *Leisure* domain shows a clinically significant difference of 1.1 points between patients' and proxies' mean scores on the LIFE-H. Since there is no real gold standard for the measurement of social participation, it is difficult to ascertain whether these systematic differences are attributable to underestimation of the difficulties by the participants who had a stroke or to overestimation by their proxies.

Results also indicate that proxies' perceptions more closely reflected those of people with stroke for the assessment of daily activities in comparison with social roles. One explanation of this finding, also suggested by other researchers (8, 18), is that daily activities are more concrete and directly observable by proxies since they are performed on a regular basis. Thus they may be assessed more objectively and accurately by proxy respondents. In this study, one specific life domain, *Interpersonal relationships*, probably significantly affected the ICC value for the social roles sub-score. The lower ICC for *Interpersonal relationships* might be explained not only by the subjectivity of this life domain, but also by the lack of variability in the data. In fact, most respondents gave a score near the maximum value of the scale (9), which may have affected the computation of the ICC. These results are consistent with those of Noreau et al. (31), who studied the reliability of the LIFE-H in older adults with disabilities. They described excellent reliability for the daily activities sub-score (test-retest: ICC: 0.96; inter-rater: ICC: 0.91) but only moderate to good for the social roles sub-score (test-retest: ICC: 0.76; inter-rater: ICC: 0.64). Again, the lack of variability in the data for *Interpersonal relationships* partly explained the lower ICC for the social roles sub-score.

Several characteristics of people who had had a stroke also appear to affect the level of agreement between members of

the dyads in this study. *Stroke severity*, estimated by CMSA scores, was found to be an important predictor of disagreement between people with stroke and proxies in all 3 regression models, thus supporting previous studies (14, 18). More specifically, the study suggests a greater association of *lower extremity* than *upper extremity impairment* with disagreement indexes. Interestingly, lower extremity abilities, such as motor coordination and balance, were also found to be among the best predictors of social participation after stroke (39). Therefore, patients showing better motor recovery of the lower extremity following stroke usually experience less disruption in participation. Assessments of social participation by these patients might be less likely to differ from their proxies' assessments since both of their scores on the LIFE-H are generally high.

Cognitive functioning of the person with stroke was identified as being the second best predictor of disagreement on the LIFE-H total score and social roles sub-score. Lower agreement between people with significant cognitive impairment and their proxies was previously found in studies including various populations of older adults (21, 22, 40). The present study shows that, among people who had a stroke but without significant cognitive deficits, those with lower cognitive performance may provide responses less comparable to proxies' assessments. In addition, results suggest that clinicians and researchers should be cautious when interpreting proxy responses, as a substitute for a person with both lower cognitive performance and severe motor disabilities, since their perceptions may differ.

The other predictors identified were related to disagreement either in daily activities or in social roles. Sociodemographic characteristics specifically associated with disagreement in daily activities included living environment (seniors' private residence) and female sex. To our knowledge, no study has previously reported statistically significant relationships between these variables and the level of agreement between people with stroke and their proxies. These findings might result from complex intercorrelations between some of the variables that we cannot clearly identify.

For social roles, disagreement between members of the dyads seemed to increase when the time since stroke onset was longer. Conversely, Pickard et al. (13) noted an improvement in patient-proxy agreement on the assessment of health-related quality of life during the first 6 months following stroke. Unlike the participants in the study by Pickard et al. (13), most of our subjects had had their stroke less recently (> 1 year) and experienced chronic functional disability. Should we suppose that patients' and proxies' perceptions evolve differently over the years following stroke? A longitudinal study examining changes in agreement between people with stroke and their proxies over a long period after stroke would be needed to answer this question.

Finally, several factors may explain the absence of relationship between proxy characteristics and disagreement indexes in this study. First, the small sample size may have reduced statistical power. Second, the study may have failed to identify some characteristics associated with disagreement due to the homogeneity of the proxy sample, composed as it was mostly of women and spouses. Third, the R^2 values, ranging from 32%

to 44%, indicate that other variables, not considered in this study, could account for disagreement between participants with stroke and their proxies on the LIFE-H. The influence of caregiver burden, for example, was not evaluated in this study and should be examined in future research.

Another limitation of the study is that the same interviewer gathered responses from patients and proxies, which might have led to unintentional rater cues and, consequently, to higher congruence of responses. To reduce this potential bias, the data collector tried to remain blind to the first interview by not consulting the questionnaires completed previously and by following exactly the same procedures for the second interview, using standardized questions. Also, since the study excluded the employment and education items of the LIFE-H, the validity of proxy responses to assess these life domains remains unknown. The computation of a valid score for the employment and education domains was limited by the fact that these items would have been applicable to only a few of the participants with stroke. It is possible that the levels of agreement for the social roles sub-score and the LIFE-H total score would be slightly different with the inclusion of these items in a larger study. Another limitation of the study is that participants were not randomly selected and recruitment sources were quite restricted, which may have affected the representativeness of the sample. Finally, since the study only included people who had disabilities following stroke, results cannot be generalized to other populations. A larger study with various populations of older adults who have disabilities would be needed to confirm these findings.

In conclusion, the satisfactory levels of agreement between members of the dyads in this study provide a good indication of the relevance of using proxy responses to estimate social participation when people with stroke cannot be interviewed. Clinicians and researchers should nevertheless remain cautious when interpreting proxy information and take into consideration factors that may contribute to disagreement between people with stroke and their proxies, such as severity of motor disabilities and patient cognitive performance. Discriminating use of information obtained from proxies, as a substitute for patients unable to respond themselves to an interview concerning their participation, would help to determine their needs and the social and rehabilitation services they might require. For research purposes, reliance on proxy responses might be considered as an alternative to excluding participants with cognitive impairment or to statistical imputation.

ACKNOWLEDGEMENTS

The authors thank those who participated in the study, which was carried out with financial support from the Canadian Institutes of Health Research (CIHR).

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APPENDIX I. Examples of life habits used in the Assessment of Life Habits (LIFE-H) (short version 3.1)

Domain	Number of items	Examples of life habits
Nutrition	4	Preparing your meals (including operating electrical appliances)
Fitness	4	Sleep (comfort, duration, continuity, etc.)
Personal care	8	Attending to your personal hygiene (washing yourself, doing your hair, taking a bath or shower, etc.) Dressing and undressing the lower half of your body (clothing, accessories, including the choice of clothes)
Communication	8	Communicating with a group of people at home or in the community (expressing needs, holding a conversation, etc.) Using a phone at home
Housing	8	Maintaining your home (cleaning, laundry, minor repairs, etc.) Maintaining the grounds of your home (lawn, garden, snow removal, etc.)
Mobility	5	Mobility on streets or sidewalks (including crossing streets) Driving a vehicle
Responsibilities	8	Planning your budget and meeting your financial obligations (spending, saving, paying bills) Assuming your personal or familial responsibilities
Interpersonal relationships	7	Maintaining close relationships with your children Maintaining friendships
Community life	8	Using your neighborhood's businesses (supermarkets, shopping malls, dry cleaners, etc.) Participating in spiritual or religious practices
Leisure	7	Participating in sports or recreational activities (walking, sports and games) Going to artistic or cultural events (concerts, movies, theatre, etc.)