

PARTICIPATION AFTER STROKE COMPARED TO NORMAL AGING

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Objective: To examine the reduction in participation of people who have had a stroke compared with healthy people with normal aging.

Design: Participation of people who had a stroke was compared with participation of healthy subjects.

Subjects/patients: Forty-six people who had a stroke for 2–4 years and 46 healthy participants matched on age, sex and living environment.

Measurements: Participation was estimated with the Assessment of Life Habits (LIFE-H). The LIFE-H (short version 2.1) is composed of 58 daily activities and social roles associated to the 12 categories of the Disability Creation Process model. The LIFE-H gives separate scores for each category, for 2 main subsections “Daily activities” and “Social roles” and a total score.

Results: Scores of healthy subjects did not reach the maximum value (9/9) of the LIFE-H, their mean scores varying from 6.3 to 8.6, according to the categories. These scores are higher than of the participants with stroke for all categories (scores varying from 3.9 to 6.5; *p*-values from 0.002 to <0.001), except the interpersonal relationships category (score of 7.8 vs 8.0) where no difference was found (*p* = 0.49). The disruption in participation after stroke varies according to the categories of the LIFE-H, but is more important in the daily activities categories.

Conclusion: The comparison of the scores obtained by the 2 groups suggests that a part of the reduction in participation in daily activities and social roles after stroke is attributable to normal aging and not entirely to the stroke itself. It helps to focus interventions on activities and roles disruption domains that are really attributable to stroke.

Key words: participation, aging, stroke.

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INTRODUCTION

Participation is a relatively new concept that has not yet received much attention from researchers in geriatrics and even less

specifically in relation to normal aging. However, in the early 1990s, Fouygeyrollas et al. (1, 2) made an important contribution to the advancement of knowledge about this concept by developing the Disability Creation Process (DCP) model and proposing an operationalization of participation by the concept of life habits (1). The DCP is a systemic model of human development based on the interaction between individuals and their environment (Fig. 1) and the situational result of this interaction, the life habits are composed of activities of daily living (ADL), such as personal care and mobility, and social roles, such as interpersonal relationships and leisure, that are valued by the person or his or her sociocultural environment. More recently, the final version of the International Classification of Functioning, Disability and Health (ICF) (3) defined participation as the person’s involvement in a life situation and presented a list of 9 activity and participation domains that have similarities with the categories of life habits presented in the DCP.

In the DCP, participation varies over time depending on the interaction between personal (intrinsic) factors (the individual’s organic system, aptitudes, identity) and environmental (extrinsic) factors (social and physical) (1). The quality of the accomplishment of a life habit is measured on a scale ranging from full participation to a total handicap situation. Participation may thus be defined as the accomplishment and engagement of a person in ADL and social roles, resulting from the interaction between personal factors and environmental factors acting as facilitators or obstacles. An obstacle in the environment can hinder the accomplishment of activities or roles and thus lead to a reduction in participation when it interacts with personal factors.

Stroke is the third leading cause of long-term disability (4) and its incidence increases markedly with aging (5). The post-stroke survival rate has increased considerably but many people will have to live with persistent physical, psychological and functional sequelae (6) that have an impact on their ADL and social roles. Some people will not be able to resume their previous activities (7), their participation in some activities will be restricted or disrupted, and they will live with serious handicap situations in various aspects of their lives. Previous studies carried out with people who had a stroke concluded to a reduction in their participation in ADL and social roles (8–12).

However, the increasing age itself may explain a decrease in participation. In a study of Desrosiers et al. (13), 189 people living in the community were evaluated with the Assessment of

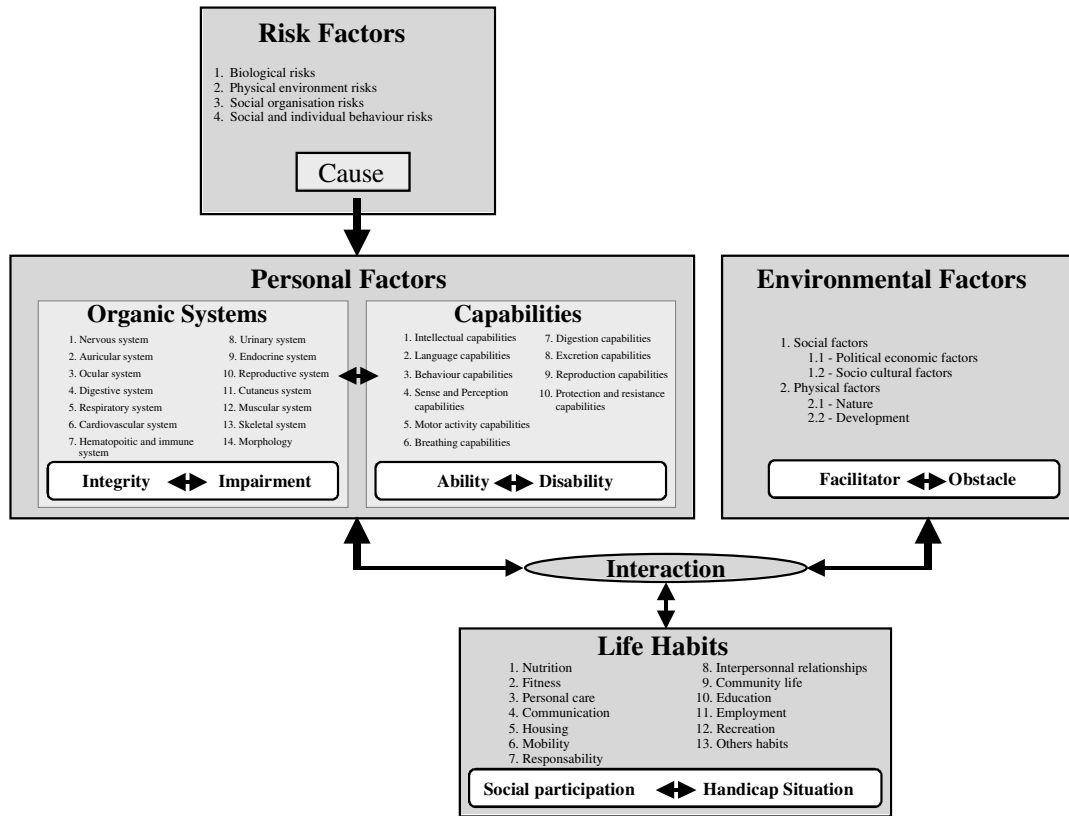


Fig. 1. The conceptual model of the disability creation process (from ref. 1 with permission).

life habits (LIFE-H), a participation measure based on the DCP model. The results indicated a statistical reduction in participation with age ($p < 0.001$) and analyses per age group showed that this reduction was mainly observed in people aged over 70–75 years. Therefore, a part of the reduction in participation with age in people who had a stroke may be attributable to the aging process since many of them are older adults. The purpose of the study was to make a distinction between the reduction in participation that can be attributable to normal aging and the additional reduction that is due to the presence of disabilities brought about by a stroke. It is important to identify and distinguish the source of participation restriction in people who have had a stroke in order to promote realistic intervention goals that will take into account the normal aging process.

METHODS

Participants

Two groups of people participated to the study: those who had a stroke and healthy people. The first group is composed of people who had a stroke, between 2–4 years previously, sufficiently important to have been hospitalized in a functional intensive rehabilitation unit. To be included in this study, that is a part of a larger comprehensive study on the long-term consequences of stroke, they had to be clinically diagnosed as having had a stroke and age 50 years or more. Moreover, given the context of a first exploration of participation in stroke people compared with normal aging, potential participants were excluded if: (i) they were unable to give their informed consent because of cognitive problems,

(ii) they could not communicate in French or English and (iii) they had severe co-morbidity problems (e.g. lower limb amputation).

The second group is composed of people without specific impairments or disabilities other than those related to normal aging (hereafter called “healthy participants”). More specifically, these participants were independent in basic ADL (eating, grooming, washing and dressing), did not present any musculoskeletal, sensory or neurological deficits, and lived at home or in a senior’s home for independent people. Each participant with stroke was matched with a healthy participant on the basis of 3 criteria: age (± 3 years), sex and living environment (own home vs senior’s home). For this last criterion, participants with stroke living in a nursing home were matched with healthy participants living in a senior’s home. Healthy participants were recruited from a database of healthy subjects at the Research Centre on Aging based on the pairing criteria and from other sources such as direct contacts with senior’s homes, posters in the research center, relatives and friends (convenience sample).

Data collection procedure

Participants were met in person in their own living environment or at the Research Centre on Aging (mainly healthy participants) for final verification of the eligibility criteria, to sign the informed consent form and to evaluate their participation with the LIFE-H (see below). Usual sociodemographic and clinical data were also collected. The research protocol has been accepted by the Research Ethics Committee of the Sherbrooke Geriatric University Institute.

Participation measurement instrument

The LIFE-H was developed to evaluate many aspects related to participation of people with or without disabilities and is based on the DCP model (1, 14–16). The short 2.1 version, composed of 58 life habits divided in 12 categories, was used. These categories (number of items) are: nutrition (3), fitness (3), personal care (4), communication (5), housing (7), mobility (3), responsibilities (7), interpersonal relationships

(7), community life (7), education (2), employment (8) and leisure (2). In the present study, the categories "employment" and "education" were combined allowing 11 different categories. The first 6 categories refer to ADL domain, whereas the others are associated with the social roles domain.

The LIFE-H score is based on 2 specific elements: (i) the degree of difficulty in carrying out life habits in a person's environment, and (ii) the type of assistance required to carry out the habits (technical assistance, physical arrangements, human help). The LIFE-H gives a continuous score ranging from 0 to 9, where 0 indicates total handicap or complete disruption in participation (meaning that the activity or the social role is not accomplished or achieved) and where 9 refers to optimal participation (meaning the activity or the social role is performed without difficulty and without assistance). Scores can be completed for each category, the 2 sub-domains (ADL and social roles) and for the instrument as a whole (total score), by calculated the mean of items that are applicable. The reliability coefficients of the global score recently studied with older adults having disabilities are excellent (ICC and 95% confidence intervals: 0.95 (0.91–0.98) for the test-retest, and 0.89 (0.80–0.93) for the inter-rater) (15). The construct validity of the LIFE-H as a participation measure was also studied (14, 16).

The LIFE-H has some similarities to other instruments such as the Impact on Participation and Autonomy Questionnaire (IPAQ) (17–19), which documents the possibility ("chance") of carrying out current activities or achieving social roles, as well as the Late-Life Function Disability Instrument (Late-Life FDI) (20, 21), which assesses the perceived difficulty related to the accomplishment of particular activities.

Statistical analyses

The first step was to describe the participants of both groups (sociodemographic and clinical characteristics). Mean and standard deviation were used for the continuous variable (age) and frequency and percentage for the categorical variables. Paired *t*-test and the test of McNemar were used to verify the presence of difference between the groups for continuous and categorical variables, respectively. The LIFE-H scores of the healthy participants and participants with stroke were calculated for each category, the 2 subdomains and as a whole, and were compared using the paired *t*-test. Ratios of each score for each pair of participants (participants with stroke/healthy participants) were also calculated and the mean and standard deviation of these ratios were established.

RESULTS

Ninety-two people, 46 per group, participated in the study. Their clinical and sociodemographic characteristics are presented in Table I. Because of the pairing strategy, participants of both groups are similar for age, sex and living environment. Although income and schooling of the healthy group as a whole are higher than those of the group with stroke when considered as independent groups, no statistical difference was found with the paired analyses, indicating that the groups were comparable on sociodemographic variables.

Data related to the degree of accomplishment of life habits (expressed by categories) are presented in Table II. Scores of healthy subjects are significantly higher than the ones of the participants with stroke (*p*-values from 0.002 to <0.001), except for the category "interpersonal relationship" (*p* = 0.49). Of a general manner, few restrictions of participation can be observed in healthy subjects, except for the category "housing" which relates to housekeeping and maintenance, and the category "leisure" wherein the mean scores are lower. The standard deviations of the mean scores reveal, however, that significant restrictions occur in a small percentage of individuals.

Table I. Sociodemographic characteristics of healthy participants and participants with stroke

	Healthy (<i>n</i> = 46)	Stroke (<i>n</i> = 46)
Age (mean(SD))	73.0 (11.4)	72.5 (11.5)
Sex (n(%))		
Male	23 (50)	23 (50)
Female	23 (50)	23 (50)
Schooling (n(%))		
1–4	1 (2.5)	3 (6.8)
5–8	6 (15.0)	17 (38.6)
9–10	10 (25.0)	7 (15.9)
11–13	12 (30.0)	13 (29.5)
14 and over	11 (27.5)	4 (9.1)
Missing data	6	2
Income (\$) (n(%))		
Less than 14,999	9 (25.7)	19 (45.2)
15,000–24,500	4 (11.4)	12 (28.6)
25,000–34,999	8 (22.9)	8 (19.0)
35,000 and over	14 (40.0)	3 (7.1)
Missing data	11	4
Living environment (n(%))		
Home alone	5 (10.9)	5 (10.9)
Home with spouse or others	22 (47.8)	22 (47.8)
Senior's home (and nursing home for participants with stroke)	19 (41.3)	19 (41.3)
Side of stroke (n(%))		
Right	–	21 (45.7)
Left	–	25 (54.3)
Previous stroke (n(%))		
Yes	–	10 (21.7)
No	–	36 (78.3)

The proportional relationships (the ratio S/H) between the 2 groups in terms of participation indicate that those with stroke have a greater level of restriction compared with the healthy individuals, particularly in the ADL sub-domain rather than in social roles. A close inspection of each ratio S/H reveals that the difference between the 2 groups varies according the categories of life habits. The level of accomplishment for the category "Education/work" in the participants with stroke does not reach a third of that of the healthy participants, suggesting serious restrictions among those with stroke who are concerned by this life domain (*n* = 17). The ratios S/H for the categories "community life" and "nutrition" are just over 0.50, suggesting significant restrictions in these life habits among the participants with stroke compared with the healthy subjects. However, for some categories of life habits (fitness, communication, leisure and responsibility) the ratio S/H is over 0.75 showing that the accomplishment is slightly or not reduced compared with the healthy participants.

DISCUSSION

The main purpose of the study was to demonstrate that restriction in participation among older adults should not be completely attributable to the disabilities induced by a disease such as stroke. It was relevant to establish the level of participation in normal aging and to compare it to that of people with stroke. To

Table II. Comparison of the accomplishment scores of the life habits categories (mean and SD) between the 2 groups of participants (stroke and healthy) and the proportional relationship (ratio S/H) between the pairs of subjects (n = 46 pairs)

	Stroke (n = 46)	Healthy (n = 46)	Ratio S/H† (stroke/healthy)	Diff (1–ratio)φ
LIFE-H (/9)	Mean (SD)	Mean (SD)	Mean (SD)	Value (95% CI)
Daily activities				
Nutrition	3.9 (2.4)	7.4 (1.6)	0.55 (0.33)***	0.45 (0.35–0.55)
Personal care	5.2 (2.6)	8.6 (0.6)	0.61 (0.29)***	0.39 (0.30–0.47)
Mobility	5.2 (3.2)	7.7 (1.5)	0.67 (0.39)***	0.33 (0.21–0.44)
Housing	4.8 (1.9)	7.1 (1.1)	0.69 (0.29)***	0.31 (0.22–0.39)
Fitness	6.1 (2.2)	8.2 (1.3)	0.75 (0.22)***	0.25 (0.18–0.31)
Communication	6.5 (2.3)	8.2 (0.8)	0.79 (0.39)**	0.21 (0.09–0.32)
Sub-score	5.2 (1.8)	7.8 (0.7)	0.67 (0.22)***	0.33 (0.26–0.39)
Social roles				
Education/employment (n = 17)	3.2 (3.9)	7.9 (2.5)	0.31 (0.48)*	0.69 (0.44–0.95)
Community life	4.4 (3.2)	8.4 (1.1)	0.53 (0.39)***	0.47 (0.35–0.48)
Leisure	3.9 (3.6)	6.3 (2.7)	0.62 (0.86)**	0.38 (0.12–0.63)
Responsibilities	6.5 (2.4)	8.3 (1.1)	0.81 (0.33)**	0.19 (0.09–0.28)
Interpersonal relationships	7.8 (1.4)	8.0 (0.9)	0.99 (0.24)	0.01 (–0.08–0.06)
Sub-score	6.0 (1.9)	7.9 (0.7)	0.76 (0.26)***	0.24 (0.16–0.31)
Total score	5.5 (1.8)	7.9 (0.7)	0.71 (0.23)***	0.29 (0.22–0.36)

p value associated to the paired t-test (* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$).

† Scores of the participants with stroke/scores of the healthy participants.

φ Difference between the value 1 and the ratio S/H. 1 is the theoretical value of equality in the 2 groups.

CI = confidence interval.

our knowledge, this is the first study that compared participation between these 2 populations and its main findings suggest that a part of the reduction in participation in ADL and social roles after stroke is attributable to normal aging and not entirely to the stroke itself, given that participation of the healthy participants was not optimal. Likewise, results also show that the restrictions of participation in ADL and social roles vary according to the life domains.

Our participants with stroke experienced chronic functional disability and all had experienced the consequences of the stroke over a period of 2–4 years. Their mean LIFE-H score of 5.5 suggests a moderate disruption of participation as a whole but clearly, some individuals with lower scores experienced more disruption in the accomplishment of their life habits. The healthy participants were in normal aging process. In order to have comparable groups, each healthy participant was matched to participants with stroke on age, sex and living environment. These 3 pairing criteria were retained since they were found to be related to participation in a previous study carried out with healthy subjects (12). The fact to live or not with others or to live in a senior's home offering some services may be important factors that can modify the engagement in ADL and social roles.

Two important issues in people with stroke are income and schooling, which are lower than in the general population (22, 23). This was also found in the present study when groups were considered as independent groups. However, in this study, income and schooling are not factors that may explain the difference of participation between the 2 groups since no statistical difference was found with paired analyses. Therefore, the pairing strategy was effective in leading to comparable pairs of participants.

The healthy participants did not reach the maximum value (9/9) of the LIFE-H, their mean scores varying from 6.3 to 8.6, according to the categories. This suggests that the maximal level of accomplishment (with no difficulty and no assistance) is not a wishful or reachable objective for all people and in all categories of life habits. Indeed, to live with other people who accomplish (entirely or partially) ADL or to decide to buy services at home (e.g. prepare meal (Nutrition) or clean the house (Housing)) may contribute to a lower degree of independence and a lower participation in specific domains without reducing quality of life, because more time may be allocated to more valued activities or social roles. At the opposite, a reduction in participation in more valued social roles such as leisure may have a negative effect on quality of life.

In general, if we exclude the education/employment category that is applicable for only 17 pairs of subjects, the group with stroke had more restriction in participation in ADL than in participation in social roles, as showed by the ratios "participants with stroke/healthy participants" (0.67 vs 0.76). This may, in part, be explained by our eligibility criterion related to cognition. Indeed, people with stroke who could not understand clearly their involvement in the study because of cognitive or phasic deficits were excluded leading to inclusion of people who have more chance to be able to keep their social roles at a good level. On the other hand, these people received in-patient rehabilitation services because of important physical impairment and disabilities leading them to lower engagement in ADL.

Participants with stroke had very low LIFE-H scores in some categories. For example, they obtained only 3.9 in the categories "Leisure" and "Nutrition". If this value was compared with a complete absence of restriction in participation (LIFE-H score

of 9), it would have suggested a significant reduction in participation compared with the “normal” way of carrying out life habits (without difficulty and assistance). However, it seems that “normality” in most older adults is not to carry out the usual life habits this way but rather to rely on a certain degree of assistance in some life domains. In leisure for example, this would have meant that the degree of participation level would be around 40% of the general population. However, comparing the LIFE-H scores of the participant with stroke with those obtained in the healthy participants, showed that people with stroke have in fact a lesser degree of restriction participation in leisure. Therefore, the comparison with the scores obtained by the healthy participants, or the ratios, allows to put the observed restriction in participation score after stroke into perspective by considering the part of the participation restriction attributable to normal aging. This comparison should consequently lead to propose more suitable and realistic objectives into the rehabilitation plans or community services for this population. It remains that some categories of participation are particularly affected by the stroke when compared with the healthy participants (e.g. education/employment, community life, leisure and nutrition). Home rehabilitation services should therefore highly consider these important life domains in order to help people with stroke to achieve a better quality of life.

Limitations of the study

This study was carried out with people not randomly selected, which may lead to a non-representative sample of both groups. Participants with stroke had received, in their subacute phase, services from an intensive rehabilitation unit. People who had a mild or, at the opposite, very severe stroke were therefore not part of the study. In addition, people who had moderate to severe cognitive deficits or who had receptive aphasia were excluded. Healthy participants were recruited in a convenience way among people who were, in some part, involved in research in our institute. They may be different from other people of their age. Since the measure of participation considers the influence of the environment, it is culture sensitive and this study was realized with a relatively homogeneous urban/semi-urban sample.

In conclusion, in this study, the comparison of the scores obtained by the participants with stroke and healthy participants suggests that a part of the reduction in participation in ADL and social roles after stroke is attributable to normal aging and not entirely to the stroke itself. It helps to focus interventions on activities and roles disruption domains that are really attributable to stroke. Further research is needed better to understand the concept of participation in normal and pathological aging.

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