Disability and quality of life of stroke survivors: evaluation nine months after

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Abstract:

Background and purpose - After acute episode, a great number of individuals who survive a stroke have impairments that impede them to carry out with autonomy a set of basic activities of daily life and instrumental activities of daily life. The clinical evaluation health self perception is a useful element on patient's recovering process. The purpose of this study was to evaluate post-stroke functional health status and quality of life.

Methods - After identification of a cohort of admitted patients at a general hospital, those were contacted by phone nine months after discharge. The collected tool sent by mail included the COOP WONCA charts, Frenchay Activities Index, Barthel Index, Rankin scale and a set of socio-demographic variables.

Results - Participants survival rate was of 81%. The physical functioning and the capacity to perform daily activities were the most affected ones, impairing the patients of making a set of basic and instrumental daily activities. The emotional state and health self-perception are also correlated to disability.

Conclusions - The results suggest a significative percentage of stroke survivors maintaining a moderate or severe disability (47.8%) requiring the presence of caregiver helping self-care. Collected data enhances that stroke survivors have severe physical dysfunction associated to emotional and psychological disturbances.

Key words: stroke, stroke recovery, disability after stroke, quality of life.

Disability and quality of life of stroke survivors: evaluation nine months after discharge

Stroke is a principal cause of Portuguese adult population mortality, having been responsible for 19.8% of the total deaths in the year 2000.[1] Patients live a mean of 5.9 years after the onset, with men presenting a 1.6 years larger survival than women.[2] First-year mortality was estimated between 15% and 25%, recurrence between 5% and 14%.[3] According to Portuguese statistics, stroke incidence is larger in males; also some epidemiological studies do mention a larger prevalence in men.[4][5][6]

After acute episode, a great number of individuals who survive a stroke have impairments that impede them to carry out with autonomy a set of basic activities of daily life (BADL) and instrumental activities of daily life (IADL). Motor impairments, cognitive and sensorial deficits, vision loss and language dysfunction, instability of humor are the most frequent disturbances after a stroke.[7] The recovery takes a long period of time and not ever succeeds. Whenever these impairments and disabilities make it impossible to carry out a set of basic activities of life, it is necessary the presence of a caregiver. The role of informal caregiver is normally assumed by the spouse, daughter or daughter-in-law.[8]

Stroke is responsible for a large health services demand and large public costs. [9] According to some authors, stroke is responsible for about 15% of all hospital admissions.[10] Beyond these problems stroke still has serious consequences in the patient's and his family's quality of life, because the sequelea don' t permit him or her the same lifestyle as before.

Given the importance and social magnitude of this disease, it becomes necessary to continue developing studies centered in the identification of risk factors, in the optimization of prevention, treatment programs, functional recovery, familiar and social reinsertion. It is also important to know the impact of the disease and its sequelea in the functional ability, the lifestyle of the individual, and how the patient perceives and values this situation. Therefore, the evaluation of the quality of life presents itself as an important healthcare outcome concerning an individual perception.[11] Although the existing divergence in the definition of

this concept, the recognition of its basic dimensions is consensual: physical function, emotional well-being and social function.[12][13]

The aim of this study was to evaluate the impact of the disease in the quality of life and functional capacity, in patients affected by stroke, nine months after hospital discharge in a Portuguese sample.

Eligible patients were those admitted with acute stroke (first or recurrent) in two Internal Medicine wards from a General Hospital in Oporto from May 2000 to May 2001, whose ages were 40 years or older, without cancer or discharge by demand.

The participants were contacted by phone nine months after clinical discharge. In that contact, we invited the participants to fill in a questionnaire, which was sent by post together with a brief explanation of the study, its purposes, ethical procedures and an envelope ready to be registered and free stamping. In the absence of a telephone contact, we got the service information. In the cases of residences without phone, we called near residences to get information and then contacted with the selected person. Even to the individuals with whom it was not possible to establish contact after 4 attempts on different days and at different hours, as well as to the ones the neighbors had no acquaintance with, were also sent questionnaires. In urban areas even residents in the same building or at close residences ignore the presence of others. The social isolation due to stroke may be a factor of non-acquaintance by the neighbors.

Measures

The perception of the quality of life was evaluated by the COOP / WONCA charts (Primary Care Cooperative Information Project/ World Organization of National Colleges, Academies).[14] [15] This scale integrates 7 domains: physical fitness, feelings, daily activities, social activities, changes in health, overall health and pain. Each domain has 5 functional levels that are illustrated with pictogrammes, lower scores indicating a higher perceived quality of life.

Autonomy grade to perform BADL and IADL was evaluated by Barthel Index (BI) and Frenchay Activities Index (FAI), respectively.[16] [17] To evaluate the handicaps, we applied the modified Scale of Rankin and a set of socio-demographic variables.[18] The BI evaluates the functional role of the individual towards 10 BADL (bowels and bladder control; personal hygiene; toilet use; eating; moving from bed to chair; moving; getting dressed; stairs and

bathing). BI ranges from 0 to 20, higher scores indicating better physical autonomy. FAI evaluates the functional ability of the individual to perform 15 domestic chores, leisure/work and outdoor activities, assessing the impact of the disease in the patient's lifestyle. Scores of FAI range from 15 to 60, higher values indicating better function. Modified Rankin scale has scores from 1 to 6, lower values showing better status.

The collected information was stored in a SPSS base (version 10.05). In the exploratory analysis data, we appealed to descriptive measures of central tendency and dispersion, as well as to parametric statistic, including measures of correlation. The comparison of means of independent groups was made with resource to the t test.[19]

The study received local ethical approval, and the subjects gave informed consent.

Results

Four hundred and seventy-seven patients were discharged after a stroke episode. The number of eligible participants was 361 and 279 agreed to participate in the study (72 died, 44 moved, had a wrong address or were institutionalized).

Due to the incomplete filling of the instrument of data collection, 6 cases were eliminated, thus remaining 273 subjects. In figure 1, we present a diagram with the information concerning the selection of the subjects.

The stroke survivors presented an average age (±SD) of 69 years old (±11.8; range, 40 to 100 years). Female participants, 45.4% (124), were older (mean 69.9±11.8) than male (mean 68.6±11.7). The characteristics in terms of distribution by classes of age, civil status, formal education, professional status, cohabitation with family members and the need for caregiver can be observed in table 1.

Figure 1 – Sample profile

Thirty-six percent (97 subjects) was filled in the questionnaire without support, 33.3% (91) referred help from a proxy (family member or friend) and 31.1% (85) did not give information. Excluding the absent participants we verify that the survival rate after 9 months was 81.1% (308/380).

Table 1 – Characterization of sample

Domain subscale scores on quality of life are presented in table 2. We verified that the means reported by the stroke survivors are globally high and therefore indicative of a perception of poor quality of life. The physical fitness was the most affected domain, while the bodily pain and the social activities were the least. Changes in health, during the two last weeks, were reported by a minority.

Table 2 - Descriptive statistics from COOP WONCA subscales

By Rankin Scale 10.7% of the individuals had no symptoms, 18.8% some symptoms that did not interfere with theirs daily activities, 16.9% had a slight disability, 11.8% a high disability and 19.1% a severe disability. By the analysis of table 3 concerning the BADL that participants can perform with autonomy, we verified that having a bath, getting dressed, climbing and descending stairs are the most changeable ones, while the most affected IADL were working, gardening and performing heavy domestic activities. In a global evaluation, we state that a lot of subjects were disabled or had a lot of difficulty in performing a set of basic domestic activities, leisure/work and outdoor activities.

Table 3 – Proportion of participants that were independent in BADL and IADL by sex

Differences by sex, between COOP WONCA subscales, Rankin, BI and FAI are shown in table 4. Men presented average low values in all domains, meaning better quality of life, but only feelings, overall health and bodily pain revealed significant differences. Men also revealed better physical function to BADL and IADL (BI, FAI and Rankin scales), although without significant differences.

Table 4 - COOP WONCA Scale, Rankin Scale, Barthel Index and Frenchay Activities Index, differences between means by sex

Age is correlated to disability to carry out domestic activities, leisure/work and outdoor activities. Quality of life perception is highly correlated to functioning (table 5). The self-perception of health status was strongly related to the emotional status (r=0.57; p<0,01) to the capacity to perform daily activities (r= 0.57; p<0,01) and als the social function (r=0.50; p<0,01).

The internal consistency of the 3 measure instruments applied, evaluated by alpha coefficient of Cronbach, presented high values, by $\alpha=0.82$ to COOP WONCA, $\alpha=0.94$ to BI and $\alpha=0.97$ to FAI.

Table 5 - Pearson correlations between scales and the age

Discussion

This study aimed to evaluate the impact of the quality of life and functional role of stroke survivors, nine months after hospital discharge. During the period of time this study reports to, it was possible to conclude that on the date of the first contact, 81% of stroke patients had survived being more significant the mortality among the female participants. [4] The great majority of the participants, 77.0% (200), classified the physical fitness that they were able to perform as light or very light. This disabled physical fitness and the disability to perform daily activities are no doubt related to the advanced age of the individuals, nevertheless these functional limitations are associated to the repercussions and sequelea of stroke.

The disturbances in the emotional status are also serious repercussions of the disease in the quality of life of the stroke survivors.[20] [21] These seem to be not only related with age but also with humor, emotional instability, anxious and depressive status associated to the disease. Some studies describe a great prevalence of post stroke depression, even 4 to 5 years later, associated to the weak recovery of the functional role and to a low perception of the quality of life in general. [21] [22] [23] [24] Depression can result either from the direct biological effect of brain infarction, such as that associated with left anterior cortex and basal ganglia lesions, or a reaction to the significant losses associated with stroke. [7]

The perceived overall health was strongly related to the emotional status, the capacity to carry out daily activities and also the social function. The least affected domain was the presence of bodily pain. Clearly, the sequelea associated to stroke are related to sensitivity problems, limb paresis and not so much with painful symptoms. Women perceived a worse quality of life in all analyzed domains, as it was proved in other published studies. [3] [25] As it was expected, the disability associated to stroke was also highly correlated. Thirty-one of stroke patients presented severe functional disablements to execute the BADL. This percentage ascends to 45.4% in these participants older than 75. Clark and Opite found similar percentage of severe disability at these ages in a sample of 567 patients with history of stroke, despite they did not use the same evaluation tool. [10]

Accounting all the cases of disabilities associated to severe functional disability to carry out BADL, this percentage ascends to 70.6%, a similar rate to the one found by O'Mahony and his collaborators, using a similar tool, the scale of Oxford Handicap (70% of the individuals presented moderate or serious disablement); however, in our study the percentage of participants requiring the presence of a caregiver to give support in basic cares for living, is lower (47.8%) than in the quoted study (56%).[26]

Although the aim of this work was not the comparison of populations, the discrepancies found make us believe that the differences in the formal chain of social support may influence the individual's perception concerning the support of a caregiver; that is to say, the perceiveness of support need has to do with the available services in the community and the ones the families can provide.

In our study no statistical differences were verified between men and women disabilities. The differences noticed are concerned to the emotional status, expressing women a greater vulnerability to depressive status and humor instability, greater sensitivity to pain, a worse perception of health and a greater limitation in social functioning. These results were also found in other studies.[27]

From the collected data we conclude that 9 months after stroke, patients have got severe physical dysfunction associated to emotional and psychological disturbances, which require the help of support programs targeted to the existing necessities and to the families but also other chains of informal support.

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Table 1 - Characterization of sample

Participants	N	%
Age (n=268)		
< 44	8	3.0
45-59	45	16.8
60-74	119	44.4
75-84	73	27.2
>85	23	8.6
Type of stroke (n =273)		
Ischemic	227	83.2
Hemorrhagic	30	11.0
Unknown	16	5.9
Formal education (n =271)		
No education	56	20.7
1-4	164	60.5
5-9	32	11.8
>10	19	7.0
Marital status: (n =270)		
Married	182	67.4
Single	11	4.1
Widow	62	23.0
Divorced	15	5.6
Employment (n=267)		
Employed	28	10.5
Not employed	239	57.3
Living arrangement (n =221)		
At home with relatives	133	60.02
At relatives' home	45	20.4
Alone	22	9.9
Other situation	21	9.5
Main caregiver (n=270)		
Spouse	112	41.5
Son or daughter	59	21.9
Other situation (social services, housemaid)	37	13.7
None	62	22.9

Table 2 –Descriptive statistics from COOP WONCA subscales

Subscales	Score 1 %	Score 2 %	Score 3 %	Score 4 %	Score 5 %	Mean	Standart Deviation
Physical fitness	1.9	3.7	16.0	36.9	41.4	4.12	0.94
Feelings	17.6	12.4	19.5	24.0	26.6	3.30	1.43
Daily activities	13.8	23.8	13.4	16.4	32.7	3.30	1.47
Social activities	37.0	13.2	14.7	13.2	21.9	2.70	1.59
Changes in health	3.0	13.5	68.2	10.9	4.5	3.00	0.74
Overall health	2.6	16.5	39.5	26.7	14.7	3.34	1.01
Bodily pain	32.5	16.2	24.2	23.4	3.8	2.50	1.26

Table 3 – Proportion of participants that were independent in BADL and IADL by sex.

	Men and Women	Women	Men
Health Status –(Barthel Index)			
Toilet	71.7	69,1	74,2
Bathing	55.1	58,1	51,6
Dressing	58.5	56,8	60,5
Eating	66.8	66,0	67,7
Transfers from - chair	73.5	73,6	73,4
Stairs	59.6	62,2	56,5
Walking	74.6	75,7	73,4
Bowels	71.7	77,0	65,3
Bladder	63.5	70,9	54,5
Going to bathroom	75.4	74,3	76,6
IADL Autonomy- (Frenchay Activities Index)			
House/car maintenance	63.4	58.1	67.8
Gainful work	14.7	10.5	18.1
Gardening	23.8	17.7	28.9
Local shopping	50.5	46.0	54.4
Pursuing hobby	56.4	51.6	60.4
Driving a car/travel on bus	64.1	59.7	67.8
Heavy housework	24.5	26.6	22.8
Reading books	51.3	41.1	59.7
Preparing meals	61.2	58.9	63.1
Washing clothes	56.8	43.5	67.8
Washing up	59.0	49.2	67.1
Outings/car rides	56.0	45.2	65.1
Light housework	59.0	56.5	61.1
Walking outdoors	62.6	56.5	67.8
Social outings	61.2	56.5	65.1

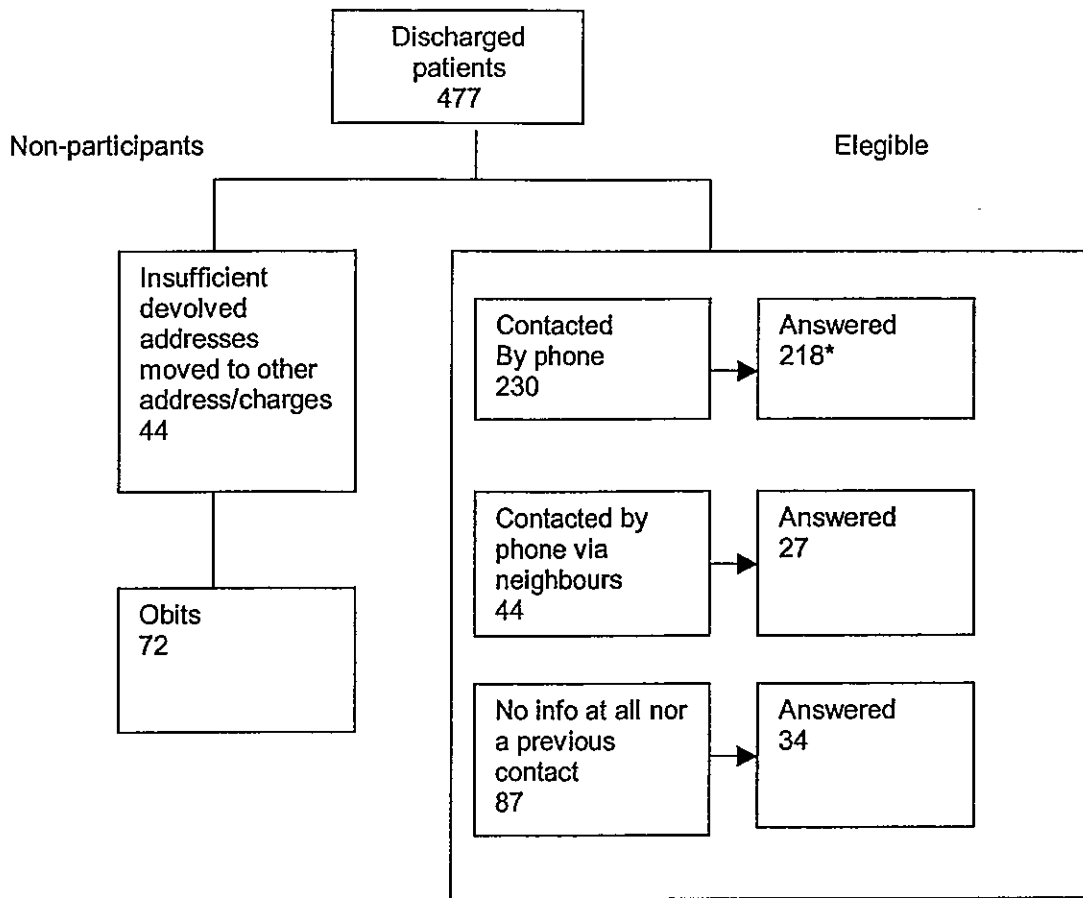Table 4 - COOP WONCA, Rankin, Barthel Index and Frenchay Activities Index, differences by sex between means

	Men and Women Mean (±SD)	Women Mean (±SD)	Men Mean (±SD)	t(p) df =271
Scale of COOP WOONCA	22.26 (5.93)	23.21(5.68)	21.25 (6.07)	2.64 **
Physical fitness	4.12 (0.94)	4.20 (0.81)	4.06 (1.03)	1.23 (ns)
Feelings	3.30 (1.43)	3.50 (1,38)	3.13 (1.45)	2.14 *
Daily activities	3.30 (1.47)	3.48 (1.34)	3.16 (1.57)	1.78 (ns)
Social activities	2.70 (1.59)	2.83 (1.57)	2.59 (1.61)	1.23 (ns)
Changes in health	3.00 (0.74)	3.06 (0.61)	2.96 (0.82)	1.21 (ns)
Overall health	3.34 (1.01)	3.50 (1.02)	3.21 (0.98)	2.38 **
Bodily pain	2.50 (1.26)	2.84 (1.26)	2.22 1.20)	4.03 ****
Rankin scale	3.58 (1.63)	3.73 (1.66)	3.45 (1.60)	1.42 (ns)
Barthel Index	15.28 (6.13)	15.07 (6.23)	15.46 (6.07)	0.52 (ns)
Frenchay Activities Index	35.17 (14.76)	34.01 (15.13)	36.13 (14.4)	1.18(ns)

*p< 0.05;   **p<0.01;   ***p<0.001

Table 5 – Pearson correlations between scales and the age

	Age	COOP WONCA
COOP WONCA: Physical fitness	0.34**	0.68**
Feelings	-0.08	0.79**
Daily activities	0.27**	0.83**
Social activities	0.06	0.77**
Changes in health	0.19**	0.47**
Overall health	0.00	0.76**
Bodily pain	0.01	0.54**
Rankin Scale	0.28**	0.70**
Barthel Index	-0.33**	-0.63**
Frenchay Activities Index	-0.42**	-0.68**

Figure 1 – Sample profile

| Discharged patients 477 |

Non-participants

Elegible

Insufficient devolved addresses moved to other address/charges 44

Obits 72

Contacted By phone 230 → Answered 218*

Contacted by phone via neighbours 44 → Answered 27

No info at all nor a previous contact 87 → Answered 34

* 6 Eliminated due to incomplete filling