The long term consequences of stroke

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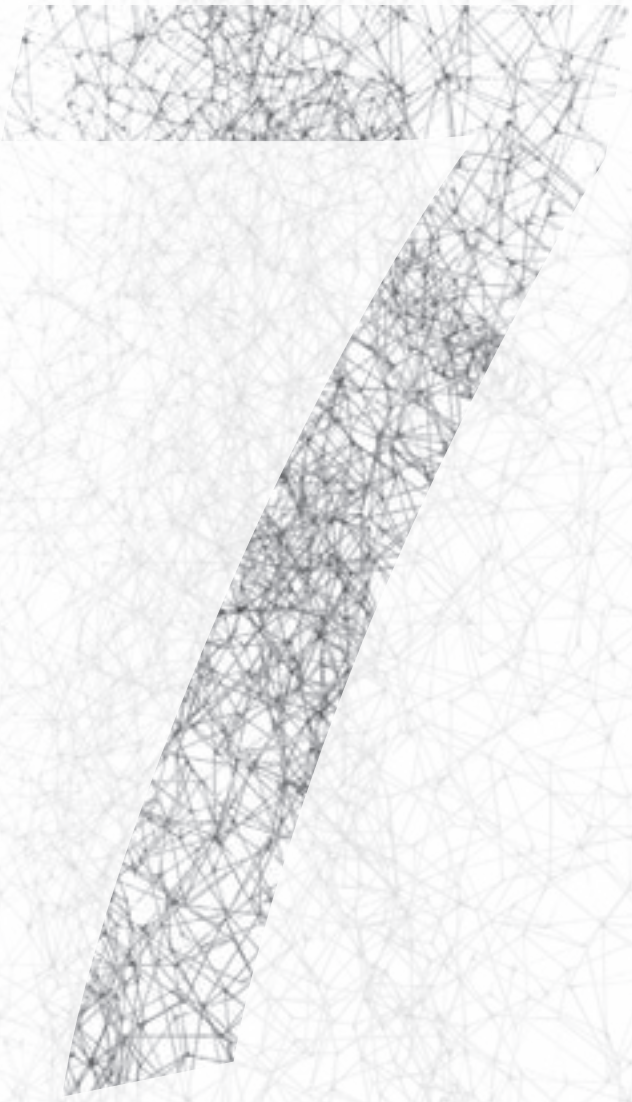

Chapter 7

Health care use and its associated factors at 5 – 8 years after stroke

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Submitted in J Stroke Cerebrovasc

Abstract

Objectives: To describe health care use and its associated factors in the chronic phase after stroke.

Methods: Patients completed a questionnaire on health care use, 5-8 years after hospital admission for stroke. It comprised the number of physicians visited (P-Use; Low ≤1 or High ≥2) and other health care professionals (HCP-Use; Low 0 or High ≥1) over the past 6 months. Moreover, the Longer-term Unmet Needs after Stroke (LUNS); Frenchay Activity Index (FAI) and the Short Form 12, from which the Physical and Mental Component Summary Scales (PCS and MCS) scores were computed, were administered. The associations between health status (FAI, PCS, MCS) and LUNS on the one side and health care use (high, low) were determined by means of logistic regression analysis, adjusted for sex and age.

Results: Of 145 eligible patients, 78 (54%) returned the questionnaires; mean time-since-stroke was 80.3 months (SD10.2), age-at-stroke 61.7 years (SD13.8), and 46 (59%) were male. Physician contacts concerned mainly the general practitioner (58;79.5%), cardiologist (10;13,5%), neurologist (8; 10.8%) and ophthalmologist (8; 10.8%). Forty-one patients (52.6%) visited ≥2 physicians; thirty-seven patients (47.4%) visited ≥1 other HCP (mainly physical therapist). Forty-four (67%) patients had one or more unmet need, mostly in non-physical domains. Higher P-Use and HCP-Use were significantly associated with worse PCS scores (OR 0.931; 95%CI 0.877-0.987 and OR 0.941; 95%CI 0.891-0.993, respectively), but not with the FAI, MCS or LUNS.

Conclusions: Health care use after stroke is substantial and is related to physical aspects of QoL, but not to mental aspects, activities or unmet needs.

Introduction

Stroke is a relatively common condition, with its outcomes ranging from full remission to severe disability and death. In many patients the personal, familial and social burden is significant and long-lasting. Long-term stroke studies have shown that five to ten years after stroke at least 30% of the patients experience a reduced level of participation in complex and social everyday activities.[1-3] Given the sustained, significant impact on many patients' health, the question arises to what extent their problems are adequately addressed by means of health care services. Regarding the latter, it has been found that stroke survivors and caregivers may feel abandoned because they have become marginalized by services.[4] Nevertheless, before the quality of health services can be improved, it is important to have insight into the actual health care use of stroke survivors.

Research into health care use in the chronic phase after stroke is however scanty. In a French observational study on stroke management, more than 60.000 stroke patients were followed regarding their health care use during the first three months after hospitalization for stroke. The health care providers that were most often visited in this period were the general practitioner (93.1%), nurse (47.3% and the physical therapist (29.6%).[5] A register-based study from Sweden, including more than 47.000 stroke patients, reported 5 visits to primary care centers for therapy in the second year after stroke.[6] In a Dutch study 232 of 352 stroke patients who were discharged from hospital to their homes (66%) visited one or more allied health professionals (i.e. physical therapists or social workers), in the first year after stroke, with a median number of visits being 20.[7] Whereas two of these studies focused only on the first year after stroke,[5,7] and two did not provide detailed data on the use of specific health professionals,[6,7] little is known about the use of specific health care providers on the longer term after stroke.

Regarding factors associated with health care use, it was found in the abovementioned Swedish study that primary health care use in the second year after stroke was not related to functioning as measured with the modified Rankin Scale at 12 months (stratified for age and level of functional disability).[6] In a study on determinants of health care use in stroke patients in the (sub)acute phase, patients with a comprehensive health insurance were more likely to have speech therapy.[8]

The large variation in the methodology and few available studies clearly indicate that a more detailed insight in, and understanding of the health care use of stroke survivors on the longer

term is needed. Furthermore, it is relevant to understand to what extent the patients' needs are adequately covered by the provided care.

The primary purpose of this study was therefore to describe health care use of community-based stroke survivors on the longer term after stroke. Secondly, the relationship of health care use with functioning, health related quality of life and unmet needs was studied.

Methods

Study design

The study was conducted at Haaglanden Medical Centre, The Hague, as an extension of a cross-sectional study on the functioning, activities, participation, coping, depression and quality of life two to five years after stroke, in patients ≥ 18 years who had been admitted to the hospital for their first-ever stroke.[9,10]

The study was judged to fall outside the Medical Research Involving Human Subjects Act by the Medical Ethics Review Committee South West Netherlands. Informed consent for study inclusion was obtained from all patients. All study procedures were executed in accordance with the Helsinki Declaration of 1975, as revised in 2013.[11]

Study population and recruitment

For the present study, the patients from the initial cohort study who had agreed to be invited to a follow-up study and who were still alive at the start of the current study were considered eligible. In 2016 (i.e. 3 years after the initial cross-sectional study) patients were invited by means of an invitation letter from the principal investigator (HA). An information leaflet, an informed consent form, and a questionnaire were enclosed. Patients who returned both the signed informed consent form and questionnaire were considered participants in the current study. Those who did not return the questionnaire within two weeks were contacted by telephone as a reminder.

Sociodemographic, clinical, and treatment-related characteristics

In the original cross-sectional study, sociodemographic, clinical, and treatment-related characteristics were derived from the hospitals' administration. These included: age at time of stroke, sex, level of education (low-intermediate-high), stroke type (hemorrhagic/

ischemic), lateralization (left hemisphere/right hemisphere/vertebro-basilar), performance in activities of daily living four days after hospital admission (Barthel Index; score range 0–20),[12] treatment with thrombolysis (yes/no), duration of hospitalization (days), and discharge destination after hospital stay (inpatient rehabilitation facility / nursing home/ versus home).

Health care use

Health care use in the last six months (contact with physicians or with other health care professionals) was assessed by means of an adapted version of a questionnaire that had been used in previous research with rheumatic diseases.[13] Patients were asked which physicians (P) they had seen in the last six months (general practitioner, neurologist, rehabilitation physician, psychiatrist, occupational physician, or other medical specialist). Furthermore, patients were asked which other primary health care professionals (HCP) were contacted in the last six months (physical therapist, occupational therapist, speech therapist, social worker, psychologist, complementary medicine/therapist, nurse, household professional, or other).

Unmet needs

The Longer-term Unmet Needs after Stroke (LUNS) questionnaire was used to identify longer-term unmet needs (UN) in the areas of information, services, social and emotional consequences, health problems, and related areas. The LUNS includes 22 statements that express a need for information or advice ("I would like advice on employment after stroke"); need for assistance or aids ("I need additional aids or adaptations inside the home"); or worries or complaints ("I am worried that I might fall [again] and this is stopping me from doing usual things"). Each item has a 'yes/no' response, with the 'no' option applying to either no need or fulfilment of a need.[14] Two-thirds of its items are being related to activities and quality of life. The LUNS was recently recently cross-culturally adapted and validated in Dutch, and was found to be acceptable, reliable and valid.[15]

Health related quality of life

The Short Form 12 (SF-12) version 1 was used to describe health related quality of life. It was adapted from the Short Form 36 (SF-36) and contains 12 items with two (yes/no) to five (always-never) outcome categories. The SF-12 is divided into a Mental Component Summary (MCS) scale (6 items) and a Physical Component Summary (PCS) scale (6 items).[16] The summary scales range from 0 to 100, where a zero score indicates the worst possible health

state and a 100 score indicates the best possible health state. The SF-12 is translated and validated into the Dutch language.[17]

Activities

The Frenchay Activities Index (FAI) was applied to evaluate household, work/leisure, and outdoor activities in the last three months (10 items) or six months (5 items), using four answering categories for each item: never (0) to most of the time (3), resulting in a total score ranging from 0 (least active) to 45 (most active). It proved to have a good construct validity and high test-retest reliability in stroke patients.[18] The Dutch version showed good reliability (Cronbach's α for the total scale 0.88) and convergent validity with the Barthel Index, an indicator of performance in activities of daily living (Pearson's r = 0.66).[19]

Data analyses

First, the sociodemographic, clinical, and stroke-related characteristics were compared between non-responders and responders by x2 tests for dichotomous and ordinal variables, and Mann-Whitney-U tests or unpaired t-tests for continuous variables, where appropriate.

Descriptive statistics (mean, SD; median, IQR; number, %) were used for health care use, unmet needs, health related quality of life and activities of the participating patients.

Health care use was dichotomized by the median number of contacts, separately for the contacts with physicians (≤1 physician visit versus ≥2; low P-Use versus high P-Use) and with other health care professionals (0 visits versus ≥1; low HCP-Use versus high HCP-Use).

Subsequently, the association between low vs high health care use (either P-Use or HCP-Use) as a dependent variable, and health status (FAI, SF12 PCS, SF12 MCS) and the total number of unmet needs (UN) as independent variables were tested by means of multivariable logistic regression analyses, adjusted for sex and age. Odds ratios (OR) and 95% confidence intervals (95%-CI) were reported.

Statistical analyses were performed using IBM SPSS Statistics, version 24.

Results

Of the 207 patients of the original study in 2013, 10 patients were deceased at follow-up and 52 patients had previously indicated not to be available for follow-up, resulting in 145 patients who were eligible for the current study. Of these patients, 78 (54%) returned the questionnaire and provided informed consent.

Table 1 shows the characteristics of the eligible patients who did and did not participate in the present study. The mean time since stroke was 80.3 months (SD 10.2, range 65 to 100). Participants and non-participants were comparable with respect to age, sex, type of stroke, Barthel Index on admission, educational level and discharge destination (p-values › 0.05).

In Table 2 the health care use of the participants in the previous six months is presented. Most of the 74 patients had visited the general practitioner in the last six months (79.5%), 41 patients (N = 58, 52.6%) visited two or more physicians (general practitioner and/or medical specialist). A small number of patients contacted a neurologist or a rehabilitation physician, eight (10.8%) and three (4.1%) respectively. Of the other medical specialists, the cardiologist and the ophthalmologist were mentioned most frequently (10, 13.5%; 8, 10.8%).

Regarding the HCP, one third of the stroke patients received treatment by a physical therapist (PT). Household professionals covering the needs with respect to household maintenance for medical reasons were ranked secondly (14.9%). Other HCP were involved less frequently (‹10%).

Most of the patients had one or more stroke-related unmet needs (N = 44, 67%). The three most common unmet needs in this study concerned: information regarding the stroke (N = 36, 46.2%); problems with memory and concentration (N = 17, 21.8%); and fear of falling (N = 17, 21.8%) (Table 3).

In Table 4 the results of the multivariable logistic regression analyses regarding health care use are presented, adjusted for age and sex. Higher scores on the SF12 PCS were associated with lower health care use (P-Use OR 0.931, 95% CI 0.877-0.987; HCP-Use OR 0.941, 95% CI 0.891-0.993). The SF12 MCS and the FAI scores as well as the number of unmet needs were not related to health care use.

Discussion

In this cross-sectional study in a hospital-based chronic stroke population (N = 74), 41 patients (52.6%) visited two or more physicians (P), and 37 patients (47.4%) visited one or more other health care professional (HCP) in the previous six months. The most frequently visited health professionals included the general practitioner (n = 58, 79.5%) and the physical therapist (n = 25, 33.8%). Less than 10% of the patients had contacted the neurologist or rehabilitation physician. Two-thirds of the patients reported one or more stroke-related needs. Health care use was related to the Physical Component Summary Score of the SF12 (PCS), but not to the Mental Component Summary Score (MCS), activities or the number of stroke-related unmet needs.

Regarding the use of specific physicians or health professionals, our results can best be compared with the study by Tuppin et al., although that study was confined to health care use in the first 6 months after stroke.[5] With respect to visits to physicians, the rates for the general practitioners, physical therapists and neurologists were comparable, whereas the proportions of patients visiting the psychiatrist or nurse were lower in the present study than in the study by Tuppin et al.

In our study 80% visited their general practitioner in the last six months, whereas less than 10% visited physicians directly related to stroke (neurologist, rehabilitation physician). Therefore, we conclude that most stroke patients were transferred to primary care, in line with the general practitioners' guideline for stroke.[20] In comparison with the study of Tuppin et al.,[5] the proportions of patients who visited the physical therapist were in the same range, the numbers of patients who visited the speech therapist were lower and the nurse much lower in the present study. Comparisons with other studies are difficult to make as they did not report the results per health care provider.[6,7]

To what extent health care systems and health insurance play a role in the present study remains unclear, as we did not assess how patients were insured. In the Netherlands, visits to physical therapist are covered by health insurance depending on additional health insurance conditions, which may have influenced our results. Observed differences in health care use in the USA may also be attributed to differences in health care systems.[8] As another example it is unusual that patients in Italy with chronic stroke are offered any form of rehabilitation.[21]

With respect to determinants of health care use, in our study a relationship with physical

functioning as measured with the SF-12, but not with FAI was found. Comparably, in the study by Lekander, no association between the modified Ranking scale and primary health care use was observed.[6]

These findings suggest that factors other than physical functioning are important in health care use. Papers from different countries and health care systems describe it as difficult for stroke patients to gain access to advice and services once discharged into the community, probably reflecting a mismatch between what patients need and what is delivered.[22]

A study by McKevitt et al reported that unmet needs of stroke survivors mainly concerned areas not typically addressed by current services.[23] On the other hand, Olaiya et al observed one or more unmet needs in over 80% of patients 2 years after stroke, and found that the number of unmet needs was positively related to the use of more community services.[24]

Relevant in this respect was the result of a systematic review of Pindus et al. demonstrating that stroke survivors and caregivers feel abandoned because they have become marginalized by services and they do not have the knowledge or skills to re-engage.[4]

In line with literature on this subject, our results show that the relations between health condition after stroke, health care needs and health care use are of a complicated nature. A variety of factors may contribute to the observed variance in health care use of stroke patient in the chronic phase such as health condition and outcome after stroke, coverage, accessibility, a lack of knowledge and coping skills in patients and carers, cultural aspects and a lack of evidence regarding therapeutical options.

The limitations of this study are related to its cross-sectional design, so causal relations cannot be established. The population was relatively small and selection bias is imminent; however, the participants in this study were comparable to the non-participants on relevant determinants. Furthermore, health care use years after stroke can result from other conditions than stroke. The strengths of this study on the other hand, are the detailed information on health care use in a hospital based population, and the relation to other outcomes on the longer term after stroke.

In conclusion, health care use among stroke patients in the Netherlands is related to

physical aspects of health related quality of life, not to mental aspects or daily activities. The observation that health care use is not related to unmet needs may lead to the conclusion that more attention should be given to the perceived needs of stroke survivors in the long term. Further research is warranted to understand which strategy enables stroke survivors to cope with their health care needs more effectively.

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Table 1. Characteristics of participants and non-participants in a follow-up study on health care use 5 to 8 years after stroke.

	Participants in follow-up study (N = 78)	Non-Participants# (N = 67)	P value*
Age at time of stroke (mean; SD)	61.7 (13.8)	63.8 (14.5)	.438
Gender (male; N, %)	46 (59.0)	44 (65.7)	.493
Mean duration of follow-up; Months (SD)	80.3 (10.2)	NA	
Educational level (N, %)			.056
- Low	22 (29.3)	27 (42.2)	
- Middle	24 (32.0)	24 (37.5)	
- High	29 (38.7)	13 (20.3)	
Type of stroke; (ischemic; N, %)	71 (91.0)	60 (89.6)	.785
Barthel Index (admission; 0-20; mean, SD)	13.6 (6.5)	12.7 (6.4)	.398
Discharge destination (home; N, %)	48 (63.2)	26 (46.4)	.076
SF-12 MCS (mean; SD) N = 65	50.0 (12.0)	NA	
SF-12 PCS (mean; SD) N = 65	43.0 (10.0)	NA	
FAI total score (mean; SD) N = 71	25.5 (11.0)	NA	
LUNS (median; IQR)	2 (4.25)	NA	

FAI, Frenchay Activities Index; SF-12, Short Form 12; MCS, Mental Component Summary score; PCS, Physical Component Summary score.

**P value of Mann-Whitney U test or chi-square test, where appropriate.*

#Non-participant= deceased or not responding to invitation

Table 2. Health care use of stroke patients; number of patients contacted a physician or a health care professional in the last 6 months.

Contact in the last 6 months with physicians:	N total	N Yes (%)
General practitioner	73	58 (79.5)
Cardiologist	74	10 (13.5)
Ophthalmologist	74	8 (10.8)
Neurologist	74	8 (10.8)
Rehabilitation physician	74	3 (4.1)
Occupational physician	74	2 (2.7)
Psychiatrist	74	4 (5.4)
Other physicians	74	22 (29.7)
- Visited no physician	78	14 (17.9)
- Visited 1 physician	78	23 (29.5)
- Visited 2 or more physicians	78	41 (52.6)
Contact in the last 6 months with health professionals:		
Physical therapist	74	25 (33.8)
Occupational therapist	74	3 (4.1)
Speech therapist	78	4 (5.1)
Psychologist	74	2 (2.7)
Social worker	73	2 (2.7)
Complementary medicine/therapist	73	3 (4.1)
Nurse	72	6 (8.3)
Household professional	74	11 (14.9)
Other type of care	74	7 (9.5)
- Visited no health care professional	78	41 (52.6)
- Visited 1 health care professional	78	17 (21.8)
- Visited 2 or more health professionals	78	20 (25.6)

Table 3. Stroke related unmet needs 5 – 8 years after stroke, previously published in Groeneveld et al.[15]

Unmet need	N (%) of participants
Information on stroke	36 (46.2)
Fear of falling	17 (21.8)
Help with concentration/ memory	17 (21.8)
Difficulties walking	15 (19.2)
Help with applying for benefits	13 (16.7)
Medication/blood checkup	13 (16.7)
Help with mood	12 (15.4)
Pain	11 (14.1)
Help with bladder/ bowel problems	11 (14.1)
Advice on diet	10 (12.8)
Information on holidays	9 (11.5)
Information on public transport	9 (11.5)
Help in household	8 (10.3)
Need for aids/ adaptations inside	8 (10.3)
Help with personal care	8 (10.3)
Advice on daily occupations	8 (10.3)
Information on moving to another home	6 (7.7)
Help with managing money	4 (5.1)
Advice on physical relationship	3 (3.8)
Need for aids/ adaptations outside	2 (2.6)
Information on driving	2 (2.6)

Table 4. Relation between health care use (contacts with physician; contacts with health care professionals and outcome after stroke (SF12; FAI; LUNS); logistic regression, crude and adjusted for age and sex.

	Physician ≤1 (SD)	Physician ≥ 2 (SD)	OR (raw)	95% CI	p	OR (corr)	95% CI	p
SF 12 PCS; n=65	46.29 (9.22)	40.33 (9.93)	0.936	0.885 – 0.990	0.020	0.931	0.877 – 0.987	0.017
SF12 MCS; n=65	52.08 (10.91)	48.31 (12.73)	0.972	0.931 – 1.016	0.213	0.970	0.927 – 1.014	0.176
FAI; n=71	26.41 (12.10)	24.71 (10.11)	0.986	0.944 – 1.030	0.518	0.995	0.951 – 1.042	0.845
LUNS Total needs; n=66	2.39 (2.68)	3.11 (3.68)	1.075	0.919 – 1.258	0.365	1.088	0.923 – 1.283	0.317
	HCP 0 (SD)	HCP ≥ 1 (SD)	OR (raw)	95% CI	p	OR (corr)	95% CI	p
SF 12 PCS; n=65	45.36 (9.72)	40.05 (9.72)	0.945	0.896 – 0.997	0.037	0.941	0.891 – 0.993	0.028
SF12 MCS; n=65	51.07 (10.73)	48.66 (13.51)	0.983	0.943 – 1.025	0.420	0.985	0.944 – 1.027	0.469
FAI; n=71	26.65 (10.09)	24.37 (11.91)	0.982	0.940 – 1.025	0.402	0.979	0.936 – 1.024	0.360
LUNS Total needs; n=66	2.64 (3.36)	2.93 (3.15)	1.029	0.885 – 1.196	0.712	1.027	0.883 – 1.194	0.732

HCP: health care professional. OR: Odd's Ratio. CI: confidence interval. SF12 PCS: Physical Component Summery Scales of the Short Form 12. SF12 MCS: Mental Component Summery Scales of the Short Form 12. FAI: Frenchay Activity Index. LUNS: Longer-term Unmet Needs after Stroke.