Health Care Use and Its Associated Factors 5-8 Years after Stroke

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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 visits to physicians or other health care professionals over the past 6 months (Physician-visits; Low ≤1 or High ≥2) and other health care professionals (Low = 0 or High ≥ 1). In addition the Longer-term Unmet Needs after Stroke (LUNS), Frenchay Activity Index (FAI) and Physical and Mental Component Summary Scales of the Short Form 12 (PCS and MCS) were administered. Their associations with health care use (high, low) were determined by means of logistic regression analysis, adjusted for sex and age. *Results:* Seventy-eight of 145 patients (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%). Forty-one (52.6%) and 37 (47.4%) of the patients had a high use of physician and other health professionals visits, respectively. Worse PCS scores were associated with both high use of physician and other health professionals visits (OR .931; 95%CI .877-.987 and OR .941; 95%CI .891-.993, respectively), whereas the FAI, MCS, or LUNS were not related to health care use. *Conclusions:* Health care use after stroke is substantial and is related to physical aspects of health status, not to mental aspects, activities or unmet needs, suggesting a mismatch between patients' needs and care delivered.

Key Words: Stroke—chronic—health care use—primary care—outcome

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 5-10 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 3 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%).[6] 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

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Received July 31, 2018; revision received May 6, 2019; accepted July 27, 2019.

Financial Disclosure: This work was supported by the research fund of the Haaglanden Medical Center (reference number 2015-1220).

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1052-3057/$ - see front matter

https://doi.org/10.1016/j.jstrokecerebrovasdis.2019.104333

stroke patients who were discharged from hospital to their homes (66%) visited 1 or more allied health professionals (ie, physical therapists or social workers), in the first year after stroke, with a median number of visits being 20.[7] Whereas 2 of these studies focused only on the first year after stroke,[5,7] and 2 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 (UN) 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 2-5 years after stroke, in patients more than or equal to 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]

Setting

In the Netherlands, the large majority of patients are hospitalized after stroke. Afterwards they are discharged to their home situation (60%), geriatric rehabilitation (30%), or inpatient medical specialist rehabilitation in a rehabilitation center (10%). Only in case of inpatient or outpatient medical specialist rehabilitation, the rehabilitation physician is involved. All patients are usually seen 6 weeks after discharge by a neurologist or clinical nurse specialist. In the chronic phase after stroke the general practitioner is leading in the health care organization and responsible for coordination according to national guidelines.

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 (H.A.). 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 2 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 4 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 6 months (contact with physicians or with other health care professionals [HCPs]) 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 they had seen in the last 6 months (general practitioner, neurologist, rehabilitation physician, psychiatrist, occupational physician, or other medical specialist). Furthermore, patients were asked which primary HCPs were contacted in the last 6 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 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 cross culturally adapted and validated in Dutch, and was found to be acceptable, reliable, and valid.[15]

Activities

The Frenchay Activities Index (FAI) was applied to evaluate household, work/leisure, and outdoor activities in the last 3 months (10 items) or 6 months (5 items), using 4 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 .88) and convergent validity with the Barthel Index, an indicator of performance in activities of daily living (Pearson's r = .66).[19]

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 and contains 12 items with 2 (yes/no) to 5 (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 0 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]

Data Analyses

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

Descriptive statistics (mean, SD; median, IQR; and number, %) were used for health care use, UN, 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 Physician-visits versus high Physician-visits) and with other HCPs (0 visits versus ≥1; low HCP-visits versus high HCP-visits).

Subsequently, the association between low versus high health care use (either Physician-visits or HCP-visits) as a dependent variable, and health status (FAI, SF-12 PCS, and SF-12 MCS) and the total number of 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 65-100). Participants and nonparticipants were comparable with respect to age, sex, type of stroke, Barthel Index on admission, educational level, and discharge destination (*P* values > .05).

In Table 2 the health care use of the participants in the previous 6 months is presented. Most of the 74 patients had visited the general practitioner in the last 6 months (79.5%), 41 patients (N = 58, 52.6%) visited 2 or more physicians (general practitioner and/or medical specialist). A small number of patients contacted a neurologist or a rehabilitation physician, 8 (10.8%) and 3 (4.1%) respectively. Of the other medical specialists, the cardiologist and the ophthalmologist were mentioned most frequently (10, 13.5%; 8, 10.8%). Forty-one patients (52.6%) visited 2 or more physicians. The general practitioner was the most frequently visited physician (n = 58, 79.5%).

Regarding the HCPs, 37 patients (47.4%) visited 1 or more other HCP in the previous six months. The physical therapist was the most frequently visited HCP (n = 25, 33.8%). 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 1 or more stroke-related UN (N = 44, 67%). The 3 most common UN 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 SF-12 PCS were associated with lower health care use

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

	Participants in follow-up study (N = 78)	Nonparticipants[#] (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
LUNS (median; IQR)	2 (4.25)	NA	
FAI total score (mean; SD) N = 71	25.5 (11.0)	NA	
SF-12 PCS (mean; SD) N = 65	43.0 (10.0)	NA	
SF-12 MCS (mean; SD) N = 65	50.0 (12.0)	NA	

FAI, Frenchay Activities Index; LUNS, Longer-Term Unmet Needs after Stroke; MCS, Mental Component Summary score; PCS, Physical Component Summary score; SF-12, Short Form 12.
*P value of Mann-Whitney U test or chi-square test, where appropriate.
[#]Nonparticipant = deceased or not responding to invitation.

(Physician-visits OR .931, 95% CI .877-.987; HCP-visits OR .941, 95% CI .891-.993). The SF-12 MCS and the FAI scores as well as the number of UN were not related to health care use.

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)

Discussion

In this cross-sectional study in a hospital-based chronic stroke population (N = 74), health care use was defined as the number of physicians and other HCPs visited in the last 6 months. A small majority of the patients visited 2 or more physicians (41 patients, 52.6%); 37 patients (47.4%) visited 1 or more HCPs, mostly the physical therapist (n = 25, 33.8%). Two thirds of the patients reported 1 or more stroke-related needs. Higher health care use (either of physicians or other HCPs) was related to worse physical functioning but not to mental functioning, daily activities, or the number of stroke-related UN.

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.[5]

In our study 80% visited their general practitioner in the last 6 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]

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)

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 physical component scale of the SF-12, but not with FAI was found. The SF-12 concerns mainly the patient's perspective of health, whereas the FAI focuses on the actual performance in daily activities. 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 other 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 health areas that are not addressed by health services.[23] On the other hand, Olaiya et al observed 1 or more UN in over 80% of patients 2 years after stroke, and found that the number of UN 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

Table 4. *Relation between the frequency of health care use (contacts with physician; contacts with health care professionals) and outcome after stroke (SF-12; FAI; LUNS); logistic regression, crude, and adjusted for age and sex*

	Health care use		Crude analysis			Adjusted analysis		
	Physician ≤1 (mean, SD)	Physician ≥ 2 (mean, SD)	OR	95% CI	*P*	OR	95% CI	*P*
LUNS Total needs; n = 66	2.39 (2.68)	3.11 (3.68)	1.075	.919-1.258	.365	1.088	.923-1.283	.317
FAI; n = 71	26.41 (12.10)	24.71 (10.11)	.986	.944-1.030	.518	.995	.951-1.042	.845
SF-12 MCS; n = 65	52.08 (10.91)	48.31 (12.73)	.972	.931-1.016	.213	.970	.927-1.014	.176
SF-12 PCS; n = 65	46.29 (9.22)	40.33 (9.93)	**.936**	**.885-.990**	**.020**	**.931**	**.877-.987**	**.017**
	HCP = 0 (mean, SD)	HCP ≥ 1 (mean, SD)	OR	95% CI	*P*	OR	95% CI	*P*
LUNS Total needs; n = 66	2.64 (3.36)	2.93 (3.15)	1.029	.885-1.196	.712	1.027	.883-1.194	.732
FAI; n = 71	26.65 (10.09)	24.37 (11.91)	.982	.940-1.025	.402	.979	.936-1.024	.360
SF-12 MCS; n = 65	51.07 (10.73)	48.66 (13.51)	.983	.943-1.025	.420	.985	.944-1.027	.469
SF-12 PCS; n = 65	45.36 (9.72)	40.05 (9.72)	**.945**	**.896-.997**	**.037**	**.941**	**.891-.993**	**.028**

CI, confidence interval; FAI, Frenchay Activity Index; HCP, health care professional; LUNS, Longer-Term Unmet Needs after Stroke; OR, odds ratio; SF-12 MCS, Mental Component Summary Scales of the Short Form 12; SF-12 PCS, Physical Component Summary scales of the short form 12.

Bold values indicate $P < 0.05$.

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 and response bias is imminent; however, the participants in this study were comparable to the nonparticipants 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 UN 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.

Acknowledgments: We are indebted to the Landsteiner Institute for support in gathering of the data.

Declaration of Competing Interest

The authors do not have any conflicts of interest to declare.

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