The Importance of Patient Involvement in Stroke Rehabilitation

Kristensen, Hanne Kaae; Tistad, Malin; Koch, Lena von; Ytterberg, Charlotte

Published in:
P L o S One

DOI:
10.1371/journal.pone.0157149

Publication date:
2016

Document version
Final published version

Document license
CC BY

Citation for published version (APA):
Kristensen, H. K., Tistad, M., Koch, L. V., & Ytterberg, C. (2016). The Importance of Patient Involvement in Stroke Rehabilitation. P L o S One, 11(6), [e0157149]. https://doi.org/10.1371/journal.pone.0157149

Terms of use
This work is brought to you by the University of Southern Denmark through the SDU Research Portal. Unless otherwise specified it has been shared according to the terms for self-archiving. If no other license is stated, these terms apply:

- You may download this work for personal use only.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying this open access version

If you believe that this document breaches copyright please contact us providing details and we will investigate your claim. Please direct all enquiries to puresupport@bib.sdu.dk

Download date: 06. May. 2020
The Importance of Patient Involvement in Stroke Rehabilitation

Hanne Kaae Kristensen1,2*, Malin Tistad3,4*, Lena von Koch3,5*, Charlotte Ytterberg2,3*

1 Health Sciences Research Centre, University College Lillebaelt, Odense, Denmark, 2 Research Unit in Rehabilitation, Institute of Clinical Research, University of Southern Denmark, Odense, Denmark, 3 Department of Neurobiology, Care Sciences and Society, Karolinska Institutet, Huddinge, Sweden, 4 School of Education, Health and Social Studies, Dalarna University, Falun, Sweden, 5 Department of Neurology, Karolinska University Hospital, Stockholm, Sweden

These authors contributed equally to this work.

* hkkr@ucl.dk

Abstract

Objective

To investigate the perceived needs for health services by persons with stroke within the first year after rehabilitation, and associations between perceived impact of stroke, involvement in decisions regarding care/treatment, and having health services needs met.

Method

Data was collected, through a mail survey, from patients with stroke who were admitted to a university hospital in 2012 and had received rehabilitation after discharge from the stroke unit. The rehabilitation lasted an average of 2 to 4.6 months. The Stroke Survivor Needs Survey Questionnaire was used to assess the participants’ perceptions of involvement in decisions on care or treatment and needs for health services in 11 problem areas: mobility, falls, incontinence, pain, fatigue, emotion, concentration, memory, speaking, reading, and sight. The perceived impact of stroke in eight areas was assessed using the Stroke Impact Scale (SIS) 3.0. Eleven logistic regression models were created to explore associations between having health services needs met in each problem area respectively (dependent variable) and the independent variables. In all models the independent variables were: age, sex, SIS domain corresponding to the dependent variable, or stroke severity in cases when no corresponding SIS domain was identified, and involvement in decisions on care and treatment.

Results

The 63 participants who returned the questionnaires had a mean age of 72 years, 33 were male and 30 were female. Eighty percent had suffered a mild stroke. The number of participants who reported problems varied between 51 (80%, mobility) and 24 (38%, sight). Involvement in decisions on care and treatment was found to be associated with having health services needs met in six problem areas: falls, fatigue, emotion, memory, speaking, and reading.
Conclusions
The results highlight the importance of involving patients in making decisions on stroke rehabilitation, as it appears to be associated with meeting their health services needs.

Introduction
Stroke is the most common cause of morbidity and long-term disability in Europe [1]. It often imposes a considerable change on people’s lives and is an economic burden to society [1]. Stroke survivors often experience physical, cognitive, social, and emotional consequences after stroke [1–3]. The healthcare offered after stroke aims to ease and support restoration of functioning and/or adaptation to disability, and to enable people with stroke to achieve optimal social integration [3–5]. Therefore, rehabilitation is an important part of these services. However, stroke survivors find themselves left with substantial activity and participation limitations and/or in need of daily help. They report long-term unmet needs for rehabilitation of up to 8 years after a stroke [6–10].

To develop high-quality healthcare for stroke survivors it is essential to have a common understanding of the needs, experiences, and priorities of those living with the results of stroke [2, 11,12]. Reviews of self-reported problems experienced by stroke survivors and their carers place strong emphasis on the social aspects of re-establishing former identities and resuming previous occupational, family, social and recreational roles [4]. Many stroke survivors and carers experience social isolation and worsening relationships with their spouses and family [13]. In addition, emotional problems, typically long-standing depressions and anxiety are common [13]. Even so, rehabilitation services seem to be aimed mostly at regaining function and, less, at enabling social participation and regaining former roles and responsibilities [11,14–17]. A survey on the prevalence of unmet needs of community-dwelling stroke survivors across the United Kingdom 1–5 years after the stroke was conducted. The survey showed that nearly half of the survivors reported one or more unmet needs related to problems with mobility, pain, fatigue, memory, and concentration [9]. Other studies have found that stroke survivors also report unmet needs related to activities of daily living (ADL). These needs are: social participation, mobility aids, home adaptation, housing, accessing financial support and benefits, information, rehabilitation and transport between 1 and 11 years after stroke [2, 7].

Clinical practice based on the best available evidence is recommended to provide high-quality service at all levels of the Danish rehabilitation organisation [4]. Evidence recommends that rehabilitation should be designed as a goal-directed, multidimensional, interdisciplinary, and cooperative practice [3, 4, 18]. International rehabilitation literature recognises a growing appreciation of including patients’ experiences and perspectives in rehabilitation practice. A person-centred practice stresses patients’ engagement, the interpersonal relationship between patient and health professionals, and ethical values [19–21]. Studies have shown that increased engagement and patient participation lead to greater satisfaction for both patient and provider. It also leads to increased adherence to health professionals’ recommendations and improved functioning [19, 22]. This is consistent with a patient, person, or client-centred perspective, which is defined as a joint practice, aimed at enabling cooperation between patients and health professionals. A person-centred perspective entails showing respect, involving and empowering the patients in shared decision-making, acting with and for them to meet their needs, and recognising patients’ experiences and knowledge [19]. Thus, hospital and city policies in Denmark are now stressing implementing structures and health policies to increase the extent to
which the rehabilitation services are based on shared decision-making and partnerships between patients and health professionals [4, 23].

Stroke rehabilitation that is based on the stroke survivors’ needs, experiences, and priorities requires extensive knowledge and skills to capture and integrate the stroke survivors’ perspectives. Few studies have explored the relationship between patients’ engagement in decision-making on rehabilitation, their perceived functioning, and needs of healthcare [2].

The purpose of this study was to explore the perceived needs for health services by people with stroke within the first year after rehabilitation. Moreover, examination of associations between perceived impact of stroke, involvement in decisions on care/treatment, and having health services needs met were undertaken.

**Materials and Methods**

The study used a survey to investigate patients’ rehabilitation experiences within Danish stroke rehabilitation practise. Data generation was based on the interdisciplinary rehabilitation offered in the different pathways, which comprise the general Danish healthcare service for adult stroke patients in hospitals as well as in community-based settings. Setting A was an in-patient stroke unit located in an acute ward at a university hospital; Setting A2 was an out-patient neurological rehabilitation department located in the same hospital (Setting A); Setting B was an in-patient rehabilitation hospital, exclusively for patients with neurological disorders; and Setting C was a local community-based rehabilitation setting. Stroke rehabilitation was organised so the individual patient could follow one of five different pathways: pathway 1 included settings A and A2; pathway 2 settings A, A2 and C; pathway 3 settings A and B; pathway 4 settings A, B and C; and pathway 5 settings A and C. Regardless of the combination of settings, the length of rehabilitation within the pathways consisting of three settings lasted approximately 4 to 4.6 months. The rehabilitation within the pathways that consisted of two settings lasted approximately 2 months. This characteristic was seen regardless of the combinations of settings, see Fig 1.

**Participants**

Inclusion criteria were adults aged 18 or over with a stroke diagnosis who had participated in a rehabilitation programme after being discharged from the acute stroke unit at a university hospital in Denmark between May 2012 and December 2012.

All participants underwent interdisciplinary rehabilitation in each of the units included in the rehabilitation pathways. Most participants were discharged from the acute stroke unit within a week and received further rehabilitation in an in-patient rehabilitation hospital exclusively for patients with neurological disorders; and the local community-based rehabilitation setting.

The therapists who offered the rehabilitation were all familiar with Danish national evidence-based guidelines, which they, according to the Danish Board of Health [4], were expected to use in their daily practice.

**Procedure**

The occupational therapists and physiotherapists in the stroke unit consecutively considered patients for inclusion in the study and informed the first author of potential participants. The first author then extracted data from the medical records of the units in the rehabilitation pathways. This was done to identify patients who had participated in rehabilitation after being discharged from the stroke unit. The survey instruments were pilot tested to strengthen the validity of the included questionnaires in a Danish context. Stressing variation concerning age,
sex, length of rehabilitation and rehabilitation pathway, 13 of the included 131 participants were chosen. The 13 participants were contacted by phone and consented to individual interviews in their own homes after end of rehabilitation by the first author using two questionnaires with closed questions. During the interviews, the participants were asked to consider the aim of the survey and to evaluate the applicability of the questionnaires. All 13 participants considered the questionnaires relevant, satisfactory and understandable in relation to the stroke rehabilitation they had undertaken. The two self-administered questionnaires were then delivered by mail to the remaining 118 participants. The mail included an information and consent letter, and a stamped, addressed envelope for returning the data. Voluntary participation was stressed. Confidentiality in the study was guaranteed and the participants were told they could withdraw at any stage. No reminders were sent. In accordance with Danish legislation on research ethics the research question, design and methods of the study did not require approval by the Research Ethics Committee. The Danish Data Protection Agency, j. no. 2007-41-0836 and the Danish Health and Medicines Authority approved the study. The study followed the directions of the Danish Board of Health.
Data collection

Data was collected on perceived impact of stroke, perceived involvement in decisions on care/treatment, and perceived health service needs between May 2012 and August 2012. The survey was undertaken between one to 12 months after the participants’ rehabilitation had ended.

Data on sex, age, hemisphere lesion, and stroke severity assessed with the Scandinavian Stroke Scale (SSS) [24, 25] on admission to the stroke unit was extracted from the medical records at the stroke unit retrospectively by the first author. The score range of the SSS is 0–58; scores of 0–25 represent severe, 26–42 moderate and 43–58 mild stroke.

The self-perceived impact of stroke was assessed using the SIS S3.0 [26]. The instrument assesses perceived impact of stroke in eight areas: strength, hand function, ADL, mobility, communication, emotion, memory and thinking, and participation. The SIS comprises 59 items scored from 1 to 5. An algorithm is used to create total scores of 0–100 for each area where 0 represents maximum impact and 100 no impact. SIS also includes a separate question about perceived recovery assessed by a scale from 0–100 where 0 stands for no recovery and 100 is fully recovered.

To assess the participants’ perceptions of involvement in decisions on care and treatment, and healthcare needs after stroke, the Stroke Survivor Needs Survey Questionnaire (SSNSQ) was used [9]. The SSNSQ consists of 44 closed questions with response categories to assess level of change or needs for healthcare in the following domains: information about stroke; health after stroke; everyday living; work and leisure; family, friends and support groups; finances and demographic information. In addition, there is one question about involvement in decisions about care and treatment. In the present study, the question about involvement in decisions regarding care and treatment, as well as 11 questions about needs for healthcare were used. The questions about needs dealt with met/unmet needs regarding 11 problems areas: mobility, falls, incontinence, pain, fatigue, emotion, concentration, memory, speaking, reading, and sight. For participants noting a problem in a specific problem area, three response choices were offered: need met, need met to some extent, need unmet. For participants wanting to be involved in decisions about care and treatment, three response choices were offered: involved, involved to some extent, not involved. The participants were asked to consider all rehabilitation related to their stroke when completing the SSNSQ.

Statistical Analysis

In all analyses the three response choices in the SSNSQ were collected into need met versus need met to some extent or need unmet, and involved versus involved to some extent or not involved. To analyse differences between participants with met and unmet needs concerning the 11 problem areas, the Mann-Whitney U-test was used for numerical data and the Chi-squared test for categorical data. The level of significance was set at p≤0.05.

Eleven logistic regression models were created to explore associations between having health services needs met with regard to each problem area respectively (dependent variable) and the independent variables. In all models the independent variables were: age, sex, SIS domain corresponding to the dependent variable, or stroke severity in cases where no corresponding SIS domain was identified, and involvement in decisions on care and treatment. Both stepwise forward and stepwise backward selections were used where variables with p≤0.05 were entered and those with p≥0.10 were removed. The Statistical Analyses Systems (SAS)® System 9.3, SAS Institute Inc., Cary, NC, USA was used for the statistical analysis.

Results

In total, 156 consecutive patients were considered for inclusion in the study of which 25 patients were excluded: 5 were deceased, two declined participation and 18 were not referred
for further rehabilitation from the acute stroke unit. Questionnaires were sent to the remaining 131 stroke survivors; 70 men and 61 women, aged 25–99, with a mean age of 72. Sixty-three participants answered and returned the questionnaires. The mean age of those who answered the questionnaires was 72 years with a range from 25 to 96 years. Thirty-three of these were men and 30 were women. Of the study participants, 80% had suffered a mild stroke, median SSS score 52. Thirty-one had right sided hemisphere lesions, 25 had a left sided, and seven had lesions in both hemispheres. The mean age of those not returning the questionnaires was also 72 years (range 43–99 years). They were equally divided concerning sex and hemisphere lesions and in the group of stroke survivors who did not return the questionnaires, 55% had suffered a mild stroke.

Table 1 shows the characteristics of participants with met and unmet needs concerning the 11 problem areas categorized with respect to the independent variables, and p values from the univariate analyses. In all problem areas except pain, most of those experiencing a problem reported unmet needs. Participants who felt they had been involved in the decisions regarding their care and treatment were more likely to report having health services needs met concerning seven problem areas: incontinence, pain, fatigue, emotion, concentration, memory, and speaking.

Results from the logistic regression analyses are shown in Table 2. The stepwise forward and the stepwise backward selection resulted in the same final models. Involvement in decisions regarding care and treatment was found to be associated with having health services needs met concerning six problem areas: falls, fatigue, emotion, memory, speaking, and reading.

Discussion

Stroke is a common, serious, and disabling health problem, and rehabilitation is a major part of patient care [3]. Even after having received rehabilitation there are indications that some stroke survivors continue perceiving unmet needs for healthcare [7]. To our knowledge, this is the first study that has explored and identified an association between stroke survivors’ involvement in decisions on care and treatment and having health services needs met concerning six problem areas: falls, fatigue, emotion, memory, speaking, and reading.

In all problem areas except pain, a majority of those experiencing problems reported unmet needs. This is in line with the results of a previous survey on the prevalence of unmet needs in community-dwelling stroke survivors 1–5 years after stroke [9]. Our results show that unmet needs occur during the first year after stroke. One plausible explanation may be that there is a lack of concurrence between the needs perceived by people with stroke and those identified by health professionals [27–30]. Some unmet needs in the present study might not have been identified by health professionals and targeted for intervention. It is also possible that participants had become aware of needs after the rehabilitation had ended.

The findings from the logistic regression models indicating high odds for having health services needs met in problem areas related to falls, fatigue, emotion, memory, speaking, and reading when the person had been involved in decisions about care and treatment, might indicate that patients’ involvement could be an important contributing factor for a favourable outcome after stroke. In the present study, it is not known whether strategies for involving patients in, for example, shared decision-making or common goal setting, were applied [3]. Shared decision-making has been described as a core ingredient in patient-centred care and a reconciliation between respect for a patient’s autonomy and the power of healthcare professionals [31]. Goal setting is also used to support patients’ autonomy and to improve patient motivation, adherence and improve satisfaction with rehabilitation [32]. In line with this, stroke survivors’ involvement in different aspects of decision-making such as goal setting and translation of

PLOS ONE | DOI:10.1371/journal.pone.0157149 June 10, 2016 6/13

PLOS ONE | DOI:10.1371/journal.pone.0157149
Table 1. Characteristics of the participants.

| Problem area | 1–12 months after stroke |  |
|--------------|--------------------------|---|
|               | Need met | Need met to some extent or Unmet | P value |
| **Mobility, n (%)** | 19 (37) | 32 (63) |  |
| Age in years, mean (sd) | 19 (37) | 73 (9) | 0.894 |
| Sex, men/women n | 0/8 | 14/17 | 0.483 |
| SIS Mobility, mean (sd) | 76 (29) | 67 (25) | 0.118 |
| **Involvement in care and treatment, n** | 7 /5 | 7/16 | 0.110 |
| **Falls, n (%)** | 14 (36) | 25 (64) |  |
| Age in years, mean (sd) | 71 (11) | 74 (9) | 0.519 |
| Sex, men/women n | 5/8 | 1/13 | 0.666 |
| SIS Mobility, mean (sd) | 76 (25) | 61 (22) | 0.046 |
| **Involvement in care and treatment, n** | 6/3 | 6/13 | 0.080 |
| **Incontinence, n (%)** | 10 (33) | 20 (67) |  |
| Age in years, mean (sd) | 76 (11) | 71 (11) | 0.183 |
| Sex, men/women n | 3/6 | 10/10 | 0.404 |
| Stroke severity, mean (sd) | 49 (7) | 49 (10) | 0.689 |
| **Involvement in care and treatment, n** | 5/2 | 2/12 | 0.009 |
| **Pain, n (%)** | 19 (51) | 18 (49) |  |
| Age in years, mean (sd) | 73 (16) | 74 (9) | 0.684 |
| Sex, men/women n | 9/8 | 9/9 | 0.862 |
| Stroke severity, mean (sd) | 46 (8) | 49 (10) | 0.121 |
| **Involvement in care and treatment, n** | 9/7 | 2/11 | 0.024 |
| **Fatigue, n (%)** | 12 (24) | 37 (76) |  |
| Age in years, mean (sd) | 71 (9) | 70 (12) | 0.701 |
| Sex, men/women n | 3/8 | 17/19 | 0.241 |
| Stroke severity, mean (sd) | 51 (8) | 48 (10) | 0.695 |
| **Involvement in care and treatment, n** | 9/12 | 5/18 | <0.001 |
| **Emotion, n (%)** | 9 (24) | 28 (76) |  |
| Age in years, mean (sd) | 75 (6) | 69 (13) | 0.132 |
| Sex, men/women n | 4/4 | 13/14 | 0.927 |
| SIS Emotion, mean (sd) | 79 (19) | 70 (24) | 0.363 |
| **Involvement in care and treatment, n** | 6/2 | 2/18 | 0.002 |
| **Concentration, n (%)** | 7 (19) | 30 (81) |  |
| Age in years, mean (sd) | 75 (11) | 69 (12) | 0.191 |
| Sex, men/women n | 2/5 | 15/14 | 0.271 |
| SIS Memory and thinking, mean (sd) | 93 (9) | 75 (21) | 0.023 |

(Continued)
goals into therapy plans has previously been reported as empowering and highly appreciated whereas authoritarian attitudes and decision-making processes had a negative influence [33–35]. However, people with stroke are not taking part in decisions about their care to the extent expected [22, 36–38] and the extent to which patients are involved in decision-making is in the hands of professionals as they lead the goal setting processes [39–42]. Nevertheless, an increased involvement by the person with stroke in decision-making and goal setting was achieved after training therapists in engaging patients in shared decision-making [43]. Such training might be needed to achieve a more shared goal setting process. Despite the lack of knowledge about specific methods used in the present study, it seems possible to involve patients in decisions about their care and rehabilitation in ordinary clinical practice which might influence to what extent health service needs are perceived to be met.

No associations were found between involvement in decisions on care and treatment and having health services needs met in problem areas related to mobility, incontinence, pain,

Table 1. (Continued)

| Problem area | 1–12 months after stroke | Need met | Need met to some extent or Unmet | P value |
|--------------|--------------------------|----------|-------------------------------|---------|
| Involvement in care and treatment, n | | | | |
| Involved/Involved to some extent or Not involved | 5/2 | 4/13 | | 0.028 |
| Memory, n (%) | | | | |
| Age in years, mean (sd) | 71 (10) | 72 (13) | | 0.864 |
| Sex, men/women, n | 3/4 | 16/14 | | 0.618 |
| SIS Memory and thinking, mean (sd) | 93 (10) | 74 (21) | | 0.016 |
| Involvement in care and treatment, n | | | | |
| Involved/Involved to some extent or Not involved | 5/2 | 3/16 | | 0.006 |
| Speaking, n (%) | | | | |
| Age in years, mean (sd) | 75 (8) | 68 (14) | | 0.160 |
| Sex, men/women, n | 2/6 | 10/12 | | 0.429 |
| SIS Communication, mean (sd) | 92 (10) | 82 (22) | | 0.429 |
| Involvement in care and treatment, n | | | | |
| Involved/Involved to some extent or Not involved | 6/2 | 3/8 | | 0.040 |
| Reading, n (%) | | | | |
| Age in years, mean (sd) | 71 (11) | 71 (13) | | 0.982 |
| Sex, men/women, n | 2/5 | 12/12 | | 0.316 |
| Stroke severity, mean (sd) | 50 (8) | 47 (10) | | 0.040 |
| Involvement in care and treatment, n | | | | |
| Involved/Involved to some extent or Not involved | 5/2 | 5/11 | | 0.074 |
| Sight, n (%) | | | | |
| Age in years, mean (sd) | 69 (9) | 72 (11) | | 0.626 |
| Sex, men/women, n | 3/3 | 11/7 | | 0.633 |
| Stroke severity, mean (sd) | 47 (10) | 51 (6) | | 0.574 |
| Involvement in care and treatment, n | | | | |
| Involved/Involved to some extent or Not involved | 4/2 | 3/9 | | 0.087 |

doi:10.1371/journal.pone.0157149.t001
### Table 2. Final logistic regression models for the association of the independent variables and met needs with regard to the 11 problem areas, odds ratios (OR) and 95% confidence intervals (CI).

| Problem area | Independent variables | Variable categorization | OR (95% CI) | Area under the receiver operating characteristic curve |
|--------------|-----------------------|-------------------------|-------------|--------------------------------------------------------|
| Mobility     | Involvement in care and treatment | Involved | 3.20 (0.75–13.66) | 0.640 |
|              |                       | Involved to some extent/Not involved | 1 | |
| Falls        | SIS mobility | Decreased impact | 1.06 (1.00–1.12) | 0.813 |
|              | Involvement in care and treatment | Involved | 13.40 (1.31–137.53) | 0.738 |
|              |                       | Involved to some extent/Not involved | 1 | |
| Incontinence | Involvement in care and treatment | Involved | 10.50 (0.67–165.11) | 0.738 |
|              |                       | Involved to some extent/Not involved | 1 | |
| Pain         | Involvement in care and treatment | Involved | 9.00 (0.81–100.11) | 0.700 |
|              |                       | Involved to some extent/Not involved | 1 | |
| Fatigue      | Involvement in care and treatment | Involved | 14.00 (1.84–106.47) | 0.787 |
|              |                       | Involved to some extent/Not involved | 1 | |
| Emotion      | Involvement in care and treatment | Involved | 22.50 (2.55–198.38) | 0.816 |
|              |                       | Involved to some extent/Not involved | 1 | |
| Concentration| SIS memory and thinking | Decreased impact | 1.12 (1.00–1.25) | 0.832 |
| Memory       | Involvement in care and treatment | Involved | 13.33 (1.71–103.75) | 0.778 |
|              |                       | Involved to some extent/Not involved | 1 | |
| Speaking     | Involvement in care and treatment | Involved | 8.00 (1.00–63.96) | 0.739 |
|              |                       | Involved to some extent/Not involved | 1 | |
| Reading      | Involvement in care and treatment | Involved | 20.00 (1.39–287.60) | 0.817 |
|              |                       | Involved to some extent/Not involved | 1 | |
| Sight        | Involvement in care and treatment | Involved | 3.50 (0.28–43.16) | 0.639 |
|              |                       | Involved to some extent/Not involved | 1 | |

doi:10.1371/journal.pone.0157149.t002
concentration, and sight. A systematic review of qualitative studies [33] stressed that physical activity in particular is valued by stroke survivors. Walking and mobility in particular were seen as important forms of physical rehabilitation [33]. Walking and mobility have also been shown to be predictors of returning to pre-stroke levels of participation [44, 45]. Though the majority of the participants in the current study had suffered a mild stroke, they might not have resumed full physical recovery. Consequently, they might have experienced lack of independence and control over their daily lives regardless of whether they had been involved in the decisions on their care and treatment. The results on incontinence and sight problems might indicate that these functions had not been assessed and identified as problem areas, or might have been present already pre-stroke, and therefore not emphasised in the stroke rehabilitation. Conversely, having health services needs met regarding reading problems, an activity that might be related to sight, was associated with involvement in decisions on care and treatment. A believable explanation for these results could be that reading problems might be more easily detected and communicated by the person with stroke. The lack of association between involvement in decisions regarding care and treatment and having health services needs met concerning pain may be explained by the fact that pain after stroke can be difficult to treat satisfactorily and has a significant negative effect on health-related quality of life [46].

A strength of the present study is the self-reported data, which gives a voice to those who are concerned. However, the results should be interpreted with caution bearing in mind that the return rate was 48% and that a larger proportion of those not returning the questionnaires had a moderate-severe stroke. As several studies have reported that people with severe impairments or disability after stroke to a larger extent report unmet needs for e.g. mobility and self-care [8,47], adaptations, physiotherapy, social life [8,9,47,48], therapy [10,11,47,48] and assistance with instrumental ADL [10], a higher return rate from people with moderate/severe stroke in the present study might have affected the findings. Contrary to these studies, severity of stroke or the impact of stroke was in the present study only associated with having health services needs met in two of the problem areas, falls and concentration. In the present study, people with aphasia might also be under-represented, as they may have found it difficult to participate in a survey based on questionnaires. Other limitations are the cross-sectional design as no firm conclusions about the direction of the association can be drawn, the limited sample size and the spread in time points to data collection. Future studies would benefit from a larger and more representative sample.

In conclusion, we found an association between stroke survivors’ self-reported involvement in decisions on care and treatment and having health services needs met for problems related to falls, fatigue, emotion, memory, speaking, and reading. As many countries have adapted policies and regulations about patient-centred care, in which involvement in decision about care and rehabilitation is a core ingredient, the issue is highly relevant but more studies are needed to further explore the association between involvement in decision making and experiences of having health services needs met.

Acknowledgments

We would like to thank The UK Stroke Association for providing the Stroke Survivor Needs Survey Questionnaire. Moreover, we thank Danish Regions and the Danish Health Cartel for funding the study.

Author Contributions

Conceived and designed the experiments: HKK MT LvK CY. Performed the experiments: HKK MT LvK CY. Analyzed the data: HKK MT LvK CY. Contributed reagents/materials/analysis tools: HKK MT LvK CY. Wrote the paper: HKK MT LvK CY.
References

1. European Stroke Organisation. [cited: February 28, 2014] Available: http://www.esostroke.org/.

2. Sumathipala K, Radcliffe E, Sadler E, Wolfe CDA, McKevitt C. Identifying the long-term needs of stroke survivors using the International Classification of Functioning, Disability and Health. Chronic Illn. 2012; 8:31–44. doi: 10.1177/1742395311423848 PMID: 22025770

3. Langhorne P, Bernhardt J, Kwakkel G. Stroke rehabilitation. Lancet. 2011; 377:1693–1702. doi: 10.1016/S0140-6736(11)60325-5 PMID: 21571152

4. Danish Board of Health. Brain Injury Rehabilitation—a health technology assessment. Danish Board of Health: Copenhagen; 2011.

5. Nordin NAM, Aziz NAA, Aziz AFA, Singh DKA, Othman NAO, Sulong S, et al. Exploring views on long-term rehabilitation for people with stroke in a developing country: findings from focus group discussions. BMC Health Serv Res. 2014; 14:118. doi: 10.1186/1472-6963-14-118 PMID: 24069911

6. Satink T, Cup EH, ilott I, Prins J, de Swart BJ, Nijhuis-van der Sanden MW. Patients’ Views on the impact of stroke on their roles and self: A thematic synthesis of qualitative studies. Arch Phys Med Rehabil. 2013; 94:1171–83. doi: 10.1016/j.apmr.2013.01.011 PMID: 23337428

7. Tistad M, Tham K, von Koch L, Ytterberg C. Unfulfilled rehabilitation needs and dissatisfaction with care 12 months after a stroke: an explorative observational study. BMC Neurol. 2012 Jun 18; 12:40. doi: 10.1186/1471-2377-12-40 PMID: 22708545

8. Duxbury S, DePaul V, Alderson M, Moreland J, Wilkins S. Individuals with stroke reporting unmet need for occupational therapy following discharge from hospital. Occup Ther Health Care. 2012; 26(19): 16–32.

9. McKevitt C, Fudge N, Redfern J, Sheldenkar A, Crichton S, Rudd AR, et al. Self-Reported long-term needs after stroke. Stroke. 2011; 42:1398–1403. doi: 10.1161/STROKEAHA.110.598839 PMID: 21441153

10. Jones F, Riazi A. Self-efficacy and self-management after stroke: a systematic review. Disabil Rehab. 2011; 33:797–810. doi: 10.3109/09638288.2010.511415 PMID: 20795919

11. Salter K, Hellings C, Foley N, Teasell R. The experience of living with stroke: a qualitative meta-synthesis. J Rehabil Med. 2008; 40: 595–602. doi: 10.2340/16501977-0238 PMID: 19020691

12. Constand MK, MacDermid JC, Bello-Haas VD, Law M. Scoping review of patient-centered care approaches in healthcare. BMC Health Serv Res. 2014; 14:271. doi: 10.1186/1472-6963-14-271 PMID: 24947822

13. Walsh ME, Galvin R, Loughnane C, Macey C, Horgan NF. Factors associated with community reintegration in the first year after stroke: a qualitative meta-synthesis. Disabil Rehab. 2015; 37:1599–1608. doi: 10.3109/09638288.2014.974834 PMID: 25382215

14. Kristensen HK, Lund H, Jones DL, Ytterberg C. ICF and the holistic perspective in stroke rehabilitation as adopted by physiotherapists and occupational therapists. Int J Ther Rehabil 2015; 22(10):460–469.

15. Kristensen HK, Ytterberg C, Jones DL, Lund H. Research-based evidence in stroke rehabilitation: an investigation of its implementation by physiotherapists and occupational therapists. Disabil Rehabil. 2015. In press.

16. Kristensen HK, Praestegaard J, Ytterberg C. Discourses in rehabilitation as they present themselves in current physiotherapy and occupational therapy. Disabil Rehabil. 2015. In press.

17. Robinson J, Wiles R, Ellis-Hill C, McPherson K, Hyndman D, Ashburn A. Resuming previously valued activities post-stroke: who or what helps? Disabil Rehabil. 2009; 31:1555–1566. doi: 10.1080/09638288.2008.1017047 PMID: 1979573

18. Momsen AM, Rasmussen JO, Nielsen CV, Iversen MD, Lund H. Multidisciplinary team care in rehabilitation: an overview of reviews. J Rehabil Med 2012; 44: 901–912. doi: 10.2340/16501977-1040 PMID: 23026978

19. Sumsion T, Law M. A review of evidence on the conceptual elements informing client-centred practice. Can J OccupTher. 2006; 73:153–162.

20. Zimmermann L, Konrad A, Müller C, Rundel M, Körner M. Patient perspectives of patient-centredness in medical rehabilitation. Patient Educ Couns. 2014; 98–105.

21. Greenhalgh T, Howick J, Maskrey N. Evidence-based medicine: a movement in crisis? BMJ. 2014; (cited 2015 Sept21); 348:g3725 doi: 10.1136/bmj.g3725. Available: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4056639/ PMID: 24927763

22. Wressle E, Eeg-Olofsson AM, Marcusson J, Henriksson C. Improved client participation in the rehabilitation process using a client-centred goal formulation structure. J Rehabil Med. 2002; 34:5–17. PMID: 11900262
23. Danish Health and Medicines Authority. Disease management programme for rehabilitation of adults with acquired brain injury:—stroke and transitory cerebral ischaemia (TCI)—trauma, infection, tumor, subarachnoidal haemorrhage and encephalopathy. Version 1.0. Copenhagen: Danish Health and Medicines Authority; 2014.

24. Govan L, Langhorne P, Weir CJ. Categorizing stroke prognosis using different stroke scales. Stroke. 2009; 40: 3396–3399. doi: 10.1161/STROKEAHA.109.557645 PMID: 19661471

25. Kasner SE. Clinical interpretation and use of stroke scales. Lancet Neurol. 2006; 5: 603–12. PMID: 16781990

26. Duncan PW, Wallace D, Lai SM, Johnson D, Embretson S, Laster LJ. The Stroke Impact Scale version 2.0. Evaluation of reliability, validity, and sensitivity to change. Stroke. 1999; 30: 2131–2140. PMID: 10512918

27. Brown M, Levack W, McPherson KM, Dean SG, Reed K, Weatherall M, et al. Survival, momentum, and things that make me 'me': patients' perceptions of goal setting after stroke. Disabil Rehabil. 2014; 36:1020–1026. doi: 10.3109/09638288.2013.825653 PMID: 23962191

28. Tistad M, Ytterberg C, Tham K, von Koch L. Poor concurrence between disabilities as described by patients and established assessment tools three months after stroke: a mixed methods approach. J Neurol Sci. 2012; 313(1–2):160–6. doi: 10.1016/j.jns.2011.08.038 PMID: 21937062

29. Talbot LR, Viscogliosi C, Desrosiers J, Vincent C, Rousseau J, Robichaud L. Identification of rehabilitation needs after a stroke: an exploratory study. Health Qual Life Outcomes. 2004; 2:53. PMID: 15383147

30. Vincent C, Deaudelin I, Robichaud L, Rousseau J, Viscogliosi C, Talbot LR, et al. Rehabilitation needs for older adults with stroke living at home: perceptions of four populations. BMC Geriatr. 2007; 7:20. PMID: 17697322

31. Godolphin W. Shared decision-making. Health Q. 2009;12 Spec No Patient(Patient):e186-90.

32. Sugavanam T, Mead G, Bulley C, Donaghy M, van Wijck F. The effects and experiences of goal setting in stroke rehabilitation—a systematic review. Disabil Rehabil. 2013; 35(3):177–90. doi: 10.3109/09638288.2012.690501 PMID: 22671934

33. Luker J, Lynch E, Bernharsson S, Bennett L, Bernhardt J. Stroke survivors’ experiences of physical rehabilitation. A systematic review of qualitative studies. Arch Phys Med Rehabil. 2015; 96:1698–708. doi: 10.1016/j.apmr.2015.03.017 PMID: 25847387

34. Levack WM, Weatherall M, Hay-Smith EJ, Dean SG, McPherson K, Siegert RJ. Goal setting and strategies to enhance goal pursuit for adults with acquired disability participating in rehabilitation. Cochrane Database Syst Rev. 2015 Jul 20; 7:CD009727. doi: 10.1002/14651858.CD009727.pub2. Review PMID: 26189709

35. Peoples H, Satink T Steultjens E. Stroke survivors’ experiences of rehabilitation: A systematic review of qualitative studies. Scand J Occup Ther. 2011; 18:163–171. doi: 10.3109/11038128.2010.509887 PMID: 20701431

36. Dworzynski K, Ritchie G, Fenu E, MacDermott K, Playford E. Rehabilitation after stroke: summary of NICE guidance. BMJ 2013; 346:f3615. doi: 10.1136/bmj.f3615 PMID: 23769695

37. National Institute for Health and Care Excellence. Stroke Rehabilitation: Long-term rehabilitation after stroke. Clinical Guideline. 2013. [cited 2015 Sept22] Available: https://www.nice.org.uk/guidance/cg162/resources/cg162-stroke-rehabilitation-full-guideline3.

38. Lindsay MP, Gubitz G, Bayley M, Hill MD, Davies-Schinkel C, Singh S, et al. Canadian best practice recommendations for stroke care (update 2010). On behalf of the Canadian stroke strategy, best practices, and standards writing group. Ottawa, Ontario Canada: Canadian Stroke Network. 2010. [cited 2015 Sept22] Available: http://www.strokebestpractices.ca/wp-content/uploads/2011/04/2010BPR_ENG.pdf.

39. Rosewilliam S, Pandyan AD, Roskell CA. Goal setting in stroke rehabilitation: Theory, practice and future directions. In Siegert RJ, Levack WMM. Eds. Rehabilitation Goal Setting—Theory, Practice and Evidence. CRC Press; 2015. p: 345–372.

40. Turner-Stokes L, Rose H, Ashford S, Singer B. Patient engagement and satisfaction with goal planning: Impact on outcome from rehabilitation. International Journal of Therapy and Rehabilitation 2015; 22:210–216.

41. Leach E, Cornwall P, Fleming J, Haines T. Patient-centered goal setting in a subacute rehabilitation setting. Disabil Rehabil. 2010; 32:159–172. doi: 10.3109/09638280903036605 PMID: 19562579

42. Rosewilliam S, Sintler C, Pandyan AD, Skelton J, Roskell CA. Is the practice of goal setting for patients in acute stroke care patient-centred and what factors influence this? A qualitative study. Clin Rehabil. 2015 May 7. pii: 0269215515584167. [Epub ahead of print].
43. Flink M, Bertilsson AS, Johansson U, Guidetti S, Tham K, von Koch L. Training in client-centeredness enhances occupational therapist documentation on goal setting and client participation in goal setting in the medical records of people with stroke. Clin Rehabil. 2015; Dec 8. pii: 0269215515620256. [Epub ahead of print].

44. Docteur E, Coulter A. Patient-centeredness in Sweden's health sytem- an external assessment in six steps for progress. Swedish Agency for Health and Care Services Analysis, 2012.

45. Singam A, Ytterberg C, Tham K, von Koch L. Participation in Complex and Social Everyday Activities Six Years after Stroke: Predictors for Return to Pre-Stroke Level. PLoS One. 2015 Dec 10; 10(12): e0144344. doi: 10.1371/journal.pone.0144344. eCollection 2015 PMID: 26658735

46. Tang WK, Lau CG, Mok V, Ungvari GS, Wong KS. The impact of pain on health-related quality of life 3 months after stroke. Topics in stroke rehabilitation. 2015 June; 22(3):194–200. doi: 10.1179/1074935714Z.0000000024 PMID: 25906672

47. van de Port IG, van den Bos GA, Voorendt M, Kwakkel G, Lindeman E. Identification of risk factors related to perceived unmet demands inpatients with chronic stroke. Disabil Rehabil. 2007; 29 (24):1841–6. PMID: 17852229

48. Kersten P, Low JT, Ashburn A, George SL, McLellan DL. The unmet needs of young people who have had a stroke: results of a national UK survey. Disabil Rehabil. 2002; 24(16):860–6. PMID: 12450462