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The long term consequences of stroke

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Chapter 6

The Longer-term Unmet Needs after Stroke Questionnaire: Cross-Cultural Adaptation, Reliability, and Concurrent Validity in a Dutch Population

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Abstract

Background: Unmet needs are common after stroke. We aimed to translate the 22-item Longer-term Unmet Needs after Stroke (LUNS) Questionnaire and validate it in a Dutch stroke population. **Methods:** The LUNS was translated and cross culturally adapted according to international guidelines. After field testing, the Dutch version was administered twice to a hospital-based cohort 5 - 8 years after stroke. Participants were also asked to complete the Frenchay Activity Index (FAI) and Short Form (SF)-12. To explore acceptability, the response and completion rates as well as number of missing items were computed. For concurrent validity, the differences in health status (FAI, SF-12) between groups who did and did not report an unmet need were calculated per item. To determine the 14-day test-retest reliability, the percentage of agreement between the first and the second administration was calculated for each item.

Results: Seventy-eight of 145 patients (53.8%) returned the initial Dutch LUNS (average age 68.3 [standard deviation 14.0] years, 59.0% male); 66 of these patients (84.6%) fully completed it. Of all items, 3.3% were missing. Among completers, the median number of unmet needs was 3.5 (2.0-5.0; 1.0-14.0). For 15 of 22 items, there was a significant association with the FAI or SF-12 Mental or Physical Component Summary scales. The percentage of agreement ranged from 69.8% to 98.1% per item.

Conclusions: Among the 53.8% who completed the survey, the LUNS was concluded to be feasible, reliable, and valid; two-thirds of its items were related to activities and quality of life. Its usefulness and acceptability when administered in routine practice require further study.

Introduction

Worldwide, stroke is one of the leading causes of death and disability.¹ Despite recent advances in stroke treatment, stroke can result in impairments in body functions, limitations in activities, and restrictions in participation² that often persist years after stroke.³ As a result, patients may still have specific needs for a long term after stroke, such as care needs and information needs. Care needs include the need for a consultation with a health professional or the need for aids or adaptations. Information needs include the need for information on stroke, on available health-care services, or on dealing with difficulties in household tasks or traveling.³

If expressed needs are not satisfied by their current service provision, they are classified as unmet.⁴ Unmet needs are relevant because they are associated with reduced quality of life for both patients⁵ and caregivers.⁶ In a cross-sectional Australian survey among 765 stroke survivors 2 years after stroke, 96% reported needs regarding the domains of health, everyday living, work, leisure, social support, and finances. Of these patients, 84% had 1 or more needs that were not fully met.⁷ In the literature, the most frequently reported unmet need concerns information on the causes and prevention of stroke.^{3,8} Other areas in which unmet needs are frequently reported include fatigue, memory, and emotion.⁹⁻¹¹ Regarding the unmet needs of Dutch stroke survivors, a multicenter study on the quality of care showed that 31% (N = 120) of non-institutionalized patients had at least 1 unmet need 6 months after stroke. Although most of these needs were resolved after 5 years, 20% of patients had the same or new unmet needs at follow-up.¹²

Until recently, no comprehensive and validated instrument existed to assess stroke survivors' unmet needs in the longer term. Therefore, the Longer-Term Stroke care (LoTS care) study team developed the Longer-term Unmet Needs after Stroke (LUNS) monitoring tool, a 22-item questionnaire concerning needs on information as well as the physical, social, and emotional consequences of stroke.¹³

Its content was based on a literature review and semi-structured interviews with stroke survivors.¹⁴ Its purpose was to detect unmet needs in stroke individuals and populations. In a previous validation study among 850 British stroke survivors 3-6 months after stroke, the LUNS was found to be acceptable (on average completed in 6 minutes; 3.5% of items missing), showed moderate to good agreement (kappa .45-.67) in test-retest analysis, and

was found to be valid based on the identification of unmet needs that were consistently related to poorer (mental) health according to the Short Form 12 (SF-12).¹³

As no translated version of the LUNS was available in the Netherlands, the objective of the present study was to translate the LUNS into Dutch and examine its psychometric properties in a hospital-based stroke population 5-8 years after stroke.

Methods

Study Design

The study consisted of 2 parts: (1) translation and cross-cultural adaptation of the LUNS and (2) determination of the psychometric properties of the Dutch language version by testing it among stroke survivors 5-8 years after stroke. The second part of the study was conducted as an extension of a cross-sectional study of the Haaglanden Medical Center that took place 3 years previously. This concerned a study on the functioning, activities, participation, coping, health-care use, and quality of life 2-5 years after stroke in patients ≥ 18 years who had been admitted to the hospital for their first-ever stroke. That study was described in greater detail in a previous publication.¹⁵

As both the previous cross-sectional study and the present study concerned a questionnaire study in which the invitees were not obliged to participate, the study was judged to fall outside the purview of 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 2013.¹⁶ The validation process of the LUNS was conducted in accordance with the COnsensus-based Standards for the selection of health Measurement Instruments criteria.¹⁷

Translation and Cross-Cultural Adaptation

Forward and Backward Translation

The process of translation and cross-cultural adaptation was based on the guidelines proposed by Beaton et al.¹⁸ First, the questionnaire was translated into Dutch independently

by a physiotherapist and physician in stroke rehabilitation (BS, PG) as well as 1 lay person (FH). For each item, they recorded their ambiguities, uncertainties, challenging phrases, and other comments. After the translation process, the principal investigator (IG) proposed a synthesis of the translations. This translated version was then translated back into English by 2 translators whose mother tongue was English, independent of the forward translators. One of them had a background in rehabilitation medicine (FM) and the other was uninformed on the topic (MG). They also recorded their comments. All of the translators strived for semantic, idiomatic, and experiential equivalence.¹⁹

Expert Revision

An expert committee consisting of a methodologist (TVV), clinical linguist (LB), translators, and principal investigator carefully read all of the translations and synthesized versions of the questionnaire. In a 2-hour meeting, they discussed the items 1 by 1 until a consensus questionnaire.

Field Testing

For the field test, a group of 20 stroke survivors with a heterogeneous composition regarding sex, age, disability type, and time since rehabilitation were invited by the principal investigator on behalf of the rehabilitation physician (PG) to fill out and comment on the prefinal version of the Dutch LUNS. First, in an open-ended question, they were asked to comment on the clarity of the questions, per item. Then, they were asked to give their opinion regarding the potential presence of overlap, contradictions, inappropriateness, or incompleteness, using closed-ended questions (yes or no). If they answered yes, they were asked to fill out the item numbers, or topics, of concern. Third, they were asked for their overall opinion on the clarity of instructions (yes or no), difficulty completing the list (not at all-a little-very), time to complete the list (minutes), and appropriateness of the font and size of letters (yes or no). Lastly, they were given the opportunity to make general remarks about the questionnaire.

If more than 1 of the patients had difficulties with an item, the expert committee would consider adapting the item. Based on the respondents' comments in the field testing phase, a final version of the questionnaire was made.

Determination of Psychometric Properties

Study Population

The study population was derived from a cross-sectional study that had taken place 3 years previously. For the present study, only the 145 patients who had agreed to be invited in case of an evolving follow-up study and who were still alive at the start of the current study were considered eligible.

Recruitment and Timing of Assessments

Eligible patients were invited by regular mail by means of an invitation letter from the principal investigator of the cross-sectional study, who is a rehabilitation physician in the Haaglanden Medical Center (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. Those who did not return the questionnaire within 2 weeks were contacted by phone.

Patients who returned the first questionnaire received a second questionnaire 2 weeks later. For the second questionnaire, no reminders were sent. If a questionnaire was not fully completed, patients were not contacted to acquire the missing information.

Assessments

The LUNS was used to identify longer term unmet needs 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”).¹³ Each item has a “yes or no” response, with the “no” option applying to either no need or fulfilment of a need. Based on Rasch and factor analysis in previous research, the original developers of the LUNS considered the scale neither suitable for calculation of a total score, nor for division into domains.²⁰

The 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 or 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).

Indicator variables of each item were weighted using regression coefficients from the general US population. The 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.²¹ In the general US population, the scales have a mean of 50 and a standard deviation of 10.

The Frenchay Activities Index (FAI) was applied to evaluate household, work or 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).³ The scale provides a sum score of 0 (least active) to 45 (most active). It has good construct validity and high test-retest reliability.²² The Dutch version, as translated by Schuling et al, showed good reliability (Cronbach α for the total scale .88) and convergent validity with the Barthel Index, an indicator of performance in activities of daily living (Pearson $r = .66$).²³

Sociodemographic, clinical, and treatment-related characteristics were derived from the hospitals' administration as part of the larger cross-sectional study. These included age at time of stroke, sex, level of education (low - intermediate - high), stroke type (hemorrhagic or ischemic), lateralization (left hemisphere or right hemisphere or vertebrobasilar), performance in activities of daily living 4 days after hospital admission (Barthel Index; score range 0-20), treatment with thrombolysis (yes or no), duration of hospitalization (days), and discharge destination after hospital stay (nursing home versus home).

Analyses

First, the sociodemographic, clinical, and treatment related characteristics were described for invited and noninvited patients as well as for responders and non-responders using means (standard deviation [SD]) and percentages. Differences between eligible and non-eligible patients and responders and non-responders were analyzed using chi-square tests for dichotomous and ordinal variables, and Mann-Whitney U tests were used to analyze continuous variables.

The overall response rate to the initial administration of the questionnaire was recorded. The number (%) of respondents who completed all of the items of the LUNS was calculated as well as the completion rates per item and number (%) of missing values. The number (%) of respondents who had 1 or more unmet needs was calculated, and the median number (interquartile range [IQR: 25th-75th percentile]; min-max) of unmet needs was reported for the respondents who completed the LUNS as a whole.

The median (IQR, min-max) scores on the FAI, SF-12 MCS, and SF-12 PCS were calculated for patients with and without unmet needs, per item. The Mann-Whitney U test was applied to detect the statistical significance of the difference in FAI and SF-12 MCS and SF-12 PCS scores between those with and without unmet needs. For each item, the proportion of observed agreement between the first and the second administration of the LUNS was calculated. As the questionnaire is used to distinguish between no unmet needs and unmet needs at the patient level instead of the population level, we did not use a reliability measure, such as Cohen kappa.²⁴

Results

Translation and Cross-Cultural Adaptation

Translation and Expert Revision

All of the translators completed their translations. In the expert meeting, several items were discussed that appeared challenging to translate literally or that raised ambiguity. After discussion, “diet” (item 12) was translated as “eetpatroon”; “home library” (item 21) was omitted; “feeling low” (item 20) was translated as “somber”; and “physical relationship” was translated as “intieme relatie.”

Field Testing

Twelve of the 15 (80%) patients who were invited to take part in the field test returned the postal questionnaire. The average duration of completion was 8 minutes. All respondents indicated that the instructions were clear and that the questionnaire was easy to fill out. None of them encountered contradictions or inappropriate questions. Three respondents noted an overlap between questions, that is, items 1 (“information on stroke”), 3 (“having pain”), 4 (“difficulties moving”), and 5 (“fear of falling”), as well as items 13 (“managing money”) and 14 (“applying for benefits”). One respondent suggested that the item on intimacy (item 18) could be changed to “sexual relationship.” One respondent noted that a question on “additional rehabilitation services” was lacking. All remarks were made by only 1 respondent. Therefore, no further discussion took place within the expert group, and no adjustments were made. The LUNS was concluded feasible for use in the target population.

Determination of Psychometric Properties

Population Characteristics

In Figure 1, a flowchart is presented. Of the original research population in the cross-sectional study ($N = 207$), 145 (70.0%) were alive and indicated a willingness to be invited for a future study. Compared with the 62 patients of the previous study who were not invited, the eligible 145 patients of the current study were somewhat younger (age at time of stroke: 62.7 versus 66.2, $P = .10$), but were otherwise comparable. Of the 145 eligible patients, 78 (53.8%) returned the set of questionnaires and informed consent form. In Table 1, the baseline characteristics of responders ($N = 78$) and non-responders ($N = 67$) to the LUNS questionnaire and differences between groups are presented. Overall, there were no significant differences between the 2 groups, except for educational level, with the proportion of higher educated patients being higher among responders (38.7%) than among nonresponders (20.3%; $P = .026$). Among responders, the average age at questionnaire completion was 68.5 (SD 14.0). Sixteen (21.1%) respondents lived alone.

Missing Items

In total, 66 participants (84.6%) completed all of the items of the LUNS at its initial administration. Ten respondents had 1-5 missing items, and 2 respondents had 19 or more missing items. Of all 78×22 items, 57 (3.3%) were missing. The percentages of missing values per item ranged from 1.3% (“information on stroke” and “information on public transport”) to 7.7% (“having pain”).

Prevalence of Unmet Needs

Of all 78 respondents who had filled out 1 or more items of the LUNS, 53 (67.9%) indicated having 1 or more unmet needs. Of the LUNS completers, 44 respondents (66.6% of 66) reported having 1 or more unmet needs, and the median number of unmet needs in this group was 3.5 (IQR 2.0-5.0; min 1.0, max 14.0). The unmet need for information on stroke was indicated most frequently ($N = 36$; 46.2%). The unmet need for information on driving and need for aids or adaptations outside was reported least frequently, by 2 (2.6%) participants.

Test-Retest Reliability

Of all 78 participants, 54 (69.2%) completed the second questionnaire (T2). On average, the interval between completion of T1 and T2 was 15.4 days (SD 4.7). As presented in Table 2, the

percentage agreement ranged from 69.8 (“information on stroke”) to 98.1 (“need for aids or adaptations outside”). In Figure 2, the percentage of respondents who indicated having an unmet need was presented for each item, for completers at T1 and T2.

Concurrent Validity

In Table 3, the results of the concurrent validity analyses are shown. For the FAI, SF-12 MCS, and SF-12 PCS, significant differences between those with and without unmet needs were found in 11, 11, and 9 items of the LUNS, respectively. In total, 15 items (68.2%) had an association with the FAI or the SF-12 MCS or the SF-12 PCS. Participants with unmet needs regarding walking, fear of falling, household tasks, bladder or bowel problems, concentration or memory, mood, and daily occupations had significantly lower scores on all 3 instruments than participants with no unmet needs on these items. Respondents with unmet needs regarding pain, public transport, money, benefits, occupation, personal care, and physical relationship did not show lower scores on any of the 3 instruments.

Discussion

In this study, we translated and cross-culturally adapted the LUNS into Dutch and assessed its psychometric properties in a heterogeneous population of stroke survivors between 5 and 8 years after stroke. Field testing yielded a comprehensive and feasible questionnaire. In a larger group, it showed high agreement between the test and the retest measurements and yielded few missing items. For 15 out of 22 items, those with unmet needs had significantly worse scores on 1 or more instruments for activities and quality of life, substantiating its validity.

The test-retest reliability of the LUNS, time needed for completion, and proportion of missing values (3.3%) appeared to be comparable with the original validation study of the LoTS care LUNS study team. Regarding the concurrent validity, in their study, 21 items were significantly associated with lower scores on the FAI or the SF-12, whereas in our study, only 15 items were.¹³

The difference in concurrent validity between the 2 studies could be related to the small size of our population combined with the small percentage of unmet time frame; 6 years after stroke, activities and quality of life can be affected by other factors than unmet needs related to stroke.

The median number of unmet needs was 3.5, and the prevalence of each unmet need ranged from 3% to 47%. Various other studies in populations 3-36 months after stroke also reported medians of 3^{9,10} or 4^{7,13} unmet needs. Interestingly, from our study, this number of unmet needs was observed much later, that is, 5-8 years after stroke.

Consistent with other studies, the prevailing need for information on stroke (“what is it, why did it happen to me, how to prevent recurrence”)⁸ was most frequently mentioned, followed by unmet needs regarding fatigue, memory or concentration, and mood.^{7,8,11} Thus, the Dutch translation of the LUNS captures unmet needs years after stroke; the amount is comparable with previous studies.

In the Netherlands, the majority of stroke patients are monitored within the health-care system for up to 1 or 2 years after stroke. After that, they drop out of sight of health professionals. From our study, it appears that it is important to continue to assess unmet needs for a longer period of time. Identifying unmet needs at the individual level will guide the provision of personalized care and information. Murray et al investigated a primary care based model. Of the 190 problems identified in 68 stroke patients and their caregivers 4-18 months post stroke onset, 75% was solved within 3 months.²⁵ Moreover, measuring unmet needs at the population level can facilitate the development and evaluation of services regarding care and information after stroke. Eventually, insight into unmet needs in the long term after stroke can be used to adapt initial stroke rehabilitation to prevent those unmet needs in future patients.

A comment that should be made regarding the content of the LUNS is that some items explicitly express the need for advice or help (e.g., “I would like outside help to get jobs done in my home”), whereas others merely express a problem (e.g., “I am worried that I might fall [again] and this is stopping me from doing my usual things”). Respondents possibly do not have a need regarding the latter issues but nevertheless have worries. Thus, the phrase “unmet needs” should be used with caution. Another remark is that an item on unmet rehabilitation needs is lacking, although this need was reported in other studies.²⁶ In future use, this item could be added to a questionnaire in addition to the LUNS. Still, the LUNS is highly informative for health professionals as it provides a comprehensive picture of all areas in which there is a desire for improvement after stroke.

The main limitation of our study is the relatively low number of respondents. For the concurrent validity analyses, this may have affected the chance of finding significant differences between groups in the FAI or SF-12 MCS or SF-12 PCS and can also explain the deviating values in some of the items. For example, the median FAI score of patients with an unmet need regarding driving (N = 2) was 7.5 (2.0-13.0), as opposed to a score of 28.0 (20.0-34.0) for patients without an unmet need. Another issue is that the responsiveness of the LUNS, for example, to patient education interventions needs further exploration.

Conclusion

Among the 53.8% who completed the survey, the LUNS was concluded to be feasible, reliable, and valid; two thirds of its items are related to activities and quality of life. Even 5-8 years after stroke, two-thirds of stroke survivors appeared to have 1 or more unmet needs. Its usefulness and acceptability when administered in routine practice require further study.

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References

1. World Health Organization. In: Mendis S, Puska P, Norrving B, eds. Global atlas on cardiovascular disease prevention and control. Geneva: WHO, 2011.
2. Geyh S, Cieza A, Schouten J, et al. ICF Core Sets for stroke. *J Rehabil Med* 2004;(44 Suppl):135-141.
3. Murray J, Ashworth R, Forster A, et al. Developing a primary care-based stroke service: a review of the qualitative literature. *Br J Gen Pract* 2003;53:137-142.
4. Heinemann AW, Sokol K, Garvin L, et al. Measuring unmet needs and services among persons with traumatic brain injury. *Arch Phys Med Rehabil* 2002;83:1052-1059.
5. Andrew NE, Kilkenny MF, Lannin NA, et al. Is health-related quality of life between 90 and 180 days following stroke associated with long-term unmet needs? *Qual Life Res* 2016;25:2053-2062.
6. Andrew NE, Kilkenny MF, Naylor R, et al. The relationship between caregiver impacts and the unmet needs of survivors of stroke. *Patient Prefer Adherence* 2015;9:1065-1073.
7. Andrew NE, Kilkenny M, Naylor R, et al. Understanding long-term unmet needs in Australian survivors of stroke. National Stroke Foundation. *Int J Stroke* 2014; 9(SupplA100):106-112.
8. Hafsteinsdóttir TB, Vergunst M, Lindeman E, et al. Educational needs of patients with a stroke and their caregivers: a systematic review of the literature. *Patient Educ Couns* 2011;85:14-25.
9. Walsh ME, Galvin R, Loughnane C, et al. Community re-integration and long-term need in the first five years after stroke: results from a national survey. *Disabil Rehabil* 2015;37:1834-1838.
10. McKeivitt C, Fudge N, Redfern J, et al. Self-reported long-term needs after stroke. *Stroke* 2011;42:1398-1403.
11. Rothwell K, Boaden R, Bamford D, et al. Feasibility of assessing the needs of stroke patients after six months using the GM-SAT. *Clin Rehabil* 2013;27:264-271.
12. Op Reimer WJ, Scholte de Haan RJ, Rijnders PT, et al. Unmet care demands as perceived by stroke patients: deficits in health care? *Qual Health Care* 1999;8:30-35.
13. LoTS care LUNS study team. Validation of the longer-term unmet needs after stroke (LUNS) monitoring tool: a multicentre study. *Clin Rehabil* 2013;27:1020-1028.
14. Murray J, Young J, Forster A, et al. Developing a primary care-based stroke model: the prevalence of longer-term problems experienced by patients and carers. *Br J Gen Pract* 2003;53:803-807.
15. Arwert HJ, Schults M, Meesters JJ, et al. Return to work 2-5 years after stroke: a cross sectional study in a hospital-based population. *J Occup Rehabil* 2017;27:239-246.
16. World Medical Association Declaration of Helsinki. Ethical principles for medical research involving human subjects. *JAMA* 2013;310:2191-2194.

17. Mokkink LB, Terwee CB, Patrick DL, et al. Cosmin Cecklist Manual. Amsterdam, Cosmin, Jan 2012. Available at: <http://www.cosmin.nl/images/upload/files/COSMIN%20checklist%20manual%20v9.pdf>. Accessed February 09, 2016.
18. Beaton DE, Bombardier C, Guillemin F, et al. Guidelines for the process of cross-cultural adaptation of self-report measures. *Spine* 2000;25:3186-3191.
19. Guillemin F, Bombardier C, Beaton D. Cross-cultural adaptation of health-related quality of life measures: literature review and proposed guidelines. *J Clin Epidemiol* 1993;46:1417-1432.
20. Forster A, Mellish K, Farrin A, et al. Project 3: Longer-term Unmet Needs after Stroke study. P77-95. In: Development and evaluation of tools and an intervention to improve patient- and carer-centred outcomes in Longer-Term Stroke care and exploration of adjustment post stroke: the LoTS care research programme. National Institute for Health Research, 2014:2-6 [Chapter 4], Programme grants for applied research.
21. Ware JE, Kosinski M, Keller SD. A 12-Item Short-Form Health Survey: construction of scales and preliminary tests of reliability and validity. *Med Care* 1996;34:220-233.
22. Turnbull JC, Kersten P, Habib M, et al. Validation of the Frenchay Activities Index in a general population aged 16 years and older. *Arch Phys Med Rehabil* 2000;81:1034-1038.
23. Schuling J, de Haan R, Limburg M, et al. The Frenchay Activities Index. Assessment of functional status in stroke patients. *Stroke* 1993;24:1173-1177.
24. de Vet HC, Mokkink LB, Terwee CB, et al. Clinicians are right not to like Cohen's κ . *BMJ* 2013;346:f2125.
25. Murray J, Young J, Forster A, et al. Feasibility study of a primary care-based model for stroke aftercare. *Br J Gen Pract* 2006;56:775-780.
26. Ullberg T, Zia E, Petersson J, et al. Perceived unmet rehabilitation needs 1 year after stroke: an observational study from the Swedish stroke register. *Stroke* 2016;47:539-541.

Figure 1. Study flow chart of a study on the cross-cultural adaptation and validation of the Longer-term Unmet Needs after Stroke (LUNS) questionnaire in a Dutch population 5-8 years after stroke.

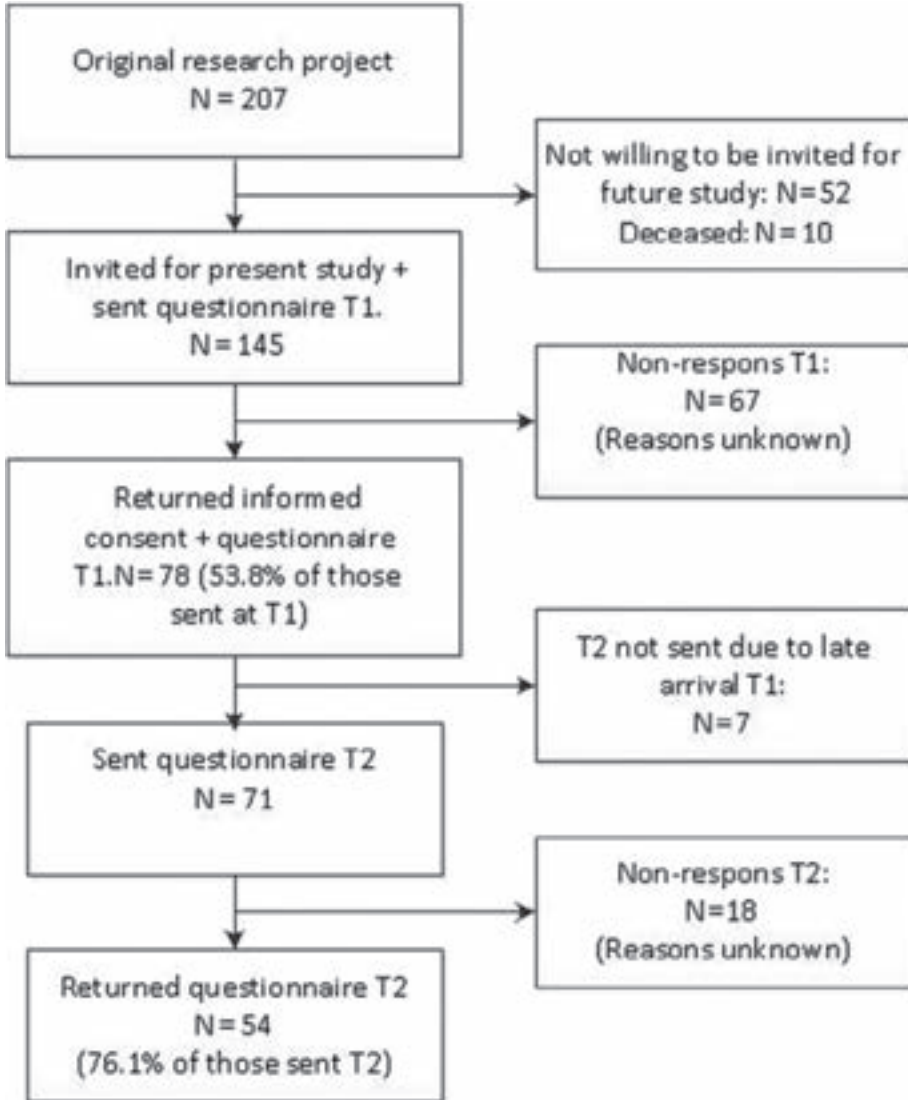


Figure 2. Percentages of stroke survivors 5-8 years after stroke (y-axis) reporting unmet needs for each of the 22 items of the Longer-term Unmet Needs after Stroke (LUNS) questionnaire, at the first assessment (T1) and the assessment 2 weeks later (T2).

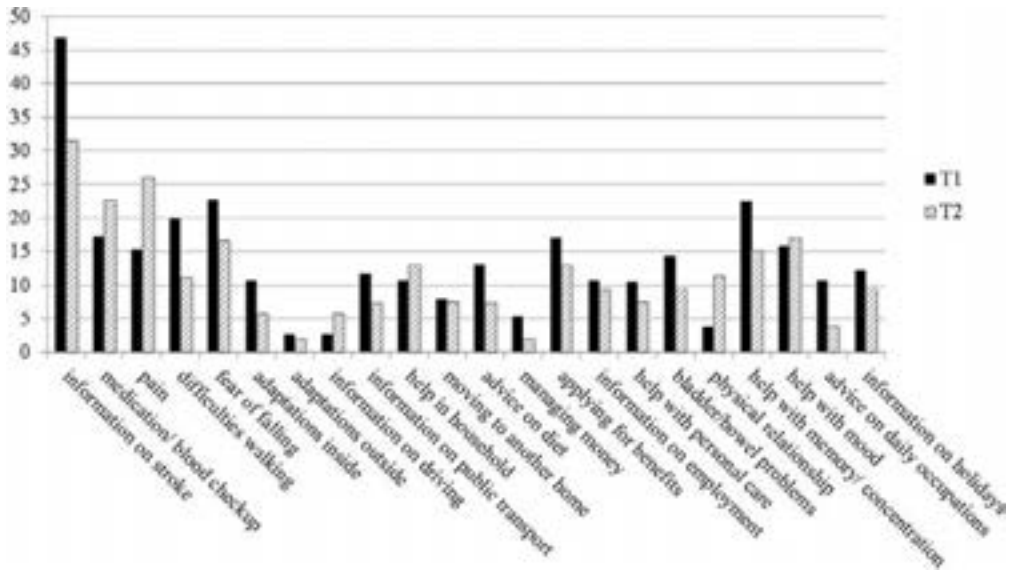


Table 1. Baseline characteristics and differences between responders and non-responders in a study on the cross-cultural adaptation and validation of the Longer-term Unmet Needs after Stroke (LUNS) questionnaire among Dutch stroke survivors 5-8 years after stroke.

	Responders (N=78)	Non-responders (N=67)	P-value*
Sex (male; N (%))	46 (59.0)	44 (65.7)	0.493
Education (N; %)			0.056 for overall comparison.
- Low	22 (29.3)	27 (42.2)	p=0.026 for high vs. other
- Intermediate	24 (32.0)	24 (37.5)	
- High	29 (38.7)	13 (20.3)	
Age at time of stroke (mean; SD)	61.7 (13.8)	63.8 (14.5)	0.438
Type of stroke (ischemic; N, %)	71 (91.0)	60 (89.6)	0.785
Received thrombolysis (N; %)	22 (28.2)	15 (25.9)	0.846
Barthel Index at day 4 after stroke (mean; SD)	13.6 (6.5)	12.7 (6.4)	0.398
Discharge destination (home; N, %)	48 (63.2)	26 (46.4)	0.076
SF-12 Mental Component Summary score (mean; SD) N=65	50.0 (12.0)	NA	
SF-12 Physical Component Summary score (mean SD) N=65	43.0 (10.0)	NA	
FAI (mean; SD) N=71	25,5 (11.0)	NA	

Table 2. The prevalence of unmet needs, the acceptability of the Longer-term Unmet Needs after Stroke (LUNS) questionnaire, and the test-retest reliability expressed as the percentage agreement between the first (T1) and the second (T2) assessment, among stroke survivors 5-8 years after stroke

	Prevalence	Missing items	Test-retest reliability
	T1.	T1.	T2-T1.
	N=78	N=78	N=54
	N (%) of respondents who indicated an unmet need	N (%) of respondents who left the item blank	Percentage agreement
Information on stroke	36 (46.2)	1 (1.3)	69.8
Medication/blood checkup	13 (16.7)	3 (3.8)	88.2
Pain	11 (14.1)	6 (7.7)	88.0
Difficulties walking	15 (19.2)	3 (3.8)	82.7
Fear of falling	17 (21.8)	3 (3.8)	86.5
Need for aids/ adaptations inside	8 (10.3)	3 (3.8)	88.7
Need for aids/ adaptations outside	2 (2.6)	3 (3.8)	98.1
Information on driving	2 (2.6)	3 (3.8)	96.2
Information on public transport	9 (11.5)	1 (1.3)	96.3
Help in household	8 (10.3)	3 (3.8)	88.7
Information on moving to another home	6 (7.7)	3 (3.8)	96.2
Advice on diet	10 (12.8)	2 (2.6)	92.5
Help with managing money	4 (5.1)	2 (2.6)	94.3
Help with applying for benefits	13 (16.7)	2 (2.6)	90.6
Information on employment	8 (10.3)	3 (3.8)	94.2
Help with personal care	8 (10.3)	2 (2.6)	92.3
Help with bladder/ bowel problems	11 (14.1)	1 (1.3)	90.6
Advice on physical relationship	3 (3.8)	2 (2.6)	92.3
Help with concentration/ memory	17 (21.8)	2 (2.6)	86.5
Help with mood	12 (15.4)	2 (2.6)	92.3
Advice on daily occupations	8 (10.3)	3 (3.8)	94.2
Information on holidays	9 (11.5)	4 (5.1)	98.0

Table 3. Concurrent validity of the Longer-term Unmet Needs after Stroke (LUNS) questionnaire among stroke survivors 5-8 years after stroke, using the SF-12 MCS, SF-12PCS and the FAI.

	SF-12 MCS scale 0-100; no unmet need- unmet need (median; IQR)	SF-12 PCS scale 0-100; no unmet need- unmet need (median; IQR)	FAI range: 0-45; no unmet need- unmet need (median; IQR)
Information on stroke	46.8 (37.6-53.9) 41.3 (34.0-46.8)	55.1 (49.8-59.8) 51.7 (40.0-56.9)	30.0 (26.0-35.0)* 26.0 (12.5-30.5)
Medication/blood checkup	45.5 (37.7-52.5) 38.2 (32.2-45.9)	55.0 (48.9-59.1)* 50.6 (32.6-51.9)	29.0 (21.0-35.0) 23.0 (16.0-30.0)
Pain	45.5 (37.6-53.6) 38.0 (28.9-44.7)	52.6 (47.8-57.9) 53.4 (33.2-59.4)	28.0 (19.0-33.0) 29.5 (21.0-35.0)
Difficulties walking	45.9 (37.7-53.6)** 36.4 (27.3-38.8)	55.0 (50.2-59.1)** 33.3 (26.5-47.8)	29.0 (23.0-35.0)** 18.0 (4.0-26.0)
Fear of falling	45.2 (37.6-53.6)* 38.6 (27.8-46.2)	54.8 (49.8-58.8)* 42.0 (29.5-54.5)	30.0 (25.0-35.0)** 12.5 (2.0-25.0)
Need for aids/ adaptations inside	45.3 (35.8-53.1)* 38.8 (27.3-43.9)	53.5 (47.8-58.7) 48.9 (26.5-56.9)	28.0 (19.0-33.0) 29.0 (14.5-33.5)
Need for aids/ adaptations outside	44.4 (35.8-52.1) 38.4 (38.4-38.4)	52.7 (47.6-58.3) 19.5 (19.5-19.5)	28.0 (20.0-34.0)* 3.0 (2.0-4.0)
Information on driving	44.9 (35.8-52.5) 36.7 (34.9-38.4)	52.8 (47.8-58.7)* 29.2 (19.5-38.9)	28.0 (20.0-34.0)* 7.5 (2.0-13.0)
Information on public transport	43.8 (35.8-52.1) 45.5 (38.8-48.3)	53.5 (48.2-58.3) 47.8 (30.4-52.3)	28.0 (19.0-33.0) 26.5 (15.0-32.5)
Help in household	45.2 (37.6-53.1)* 35.4 (27.3-38.4)	54.8 (47.8-58.8)* 45.3 (34.8-51.9)	29.0 (21.0-35.0)* 17.5 (8.5-25.5)
Information on moving to another home	45.5 (38.4-53.1)** 32.2 (27.9-35.4)	54.8 (48.9-58.8)** 37.5 (28.5-51.6)	29.0 (19.5-34.5) 23.0 (18.0-26.0)
Advice on diet	43.9 (35.8-52.5) 41.7 (35.8-47.0)	52.8 (47.4-58.7) 51.9 (39.4-57.4)	29.0 (23.0-35.0)** 18.0 (6.5-24.5)
Help with managing money	44.4 (35.8-52.5) 38.8 (27.3-47.0)	52.7 (47.4-58.7) 51.6 (30.4-57.4)	28.0 (19.0-34.0) 26.0 (25.0-29.0)
Help with applying for benefits	45.2 (35.8-52.5) 39.1 (32.4-43.9)	54.3 (47.8-58.7) 51.4 (28.5-54.8)	28.5 (20.0-35.0) 26.0 (17.0-31.0)
Information on employment	44.9 (35.8-53.1) 39.3 (35.8-48.3)	54.3 (47.4-57.9) 49.6 (19.5-51.9)	28.0 (20.0-33.0) 28.0 (2.0-34.0)
Help with personal care	45.1 (37.5-53.1) 40.7 (27.0-46.6)	53.5 (47.4-58.8) 51.3 (34.8-56.4)	28.0 (21.0-34.0) 19.0 (10.0-31.0)
Help with bladder/ bowel problems	45.9 (37.6-53.1)** 37.1 (26.7-39.7)	54.8 (49.6-58.8)** 32.6 (26.6-51.6)	29.0 (21.0-34.0)* 19.0 (4.0-29.0)
Advice on physical relationship	44.4 (35.8-51.7) 37.5 (27.3-52.5)	53.5 (47.4-58.7) 49.6 (24.9-51.6)	28.0 (19.0-33.0) 26.0 (17.0-40.0)
Help with concentration/ memory	46.8 (37.7-53.8)** 38.0 (35.4-41.9)	55.0 (50.2-58.7)** 35.5 (24.9-51.9)	29.0 (24.0-35.0)** 18.5 (16.0-25.0)
Help with mood	45.9 (37.7-53.1)** 37.5 (31.9-38.6)	55.0 (50.2-58.8)** 26.7 (22.1-32.6)	29.0 (22.5-35.0)** 17.0 (5.0-23.0)
Advice on daily occupations	45.7 (37.6-53.1)* 36.7 (29.4-38.4)	54.9 (47.8-58.8)* 41.0 (24.9-51.9)	29.0 (21.0-35.0)* 19.0 (4.0-26.0)
Information on holidays	46.2 (37.5-53.4)* 38.4 (27.3-39.3)	54.9 (49.3-58.8)* 38.9 (26.5-52.5)	28.5 (20.5-34.5) 25.0 (4.0-32.0)

