

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

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*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. **Key Words:** Stroke—unmet needs—validation studies—needs assessment—surveys and questionnaires.

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Received May 15, 2017; revision received August 15, 2017; accepted August 26, 2017.

Grant support: This work was supported by the research fund of the Haaglanden Medical Center [reference number 2015-122].

Conflict of interest: The authors declare that there is no conflict of interest.

Author contributions: I. Groeneveld formulated the research questions, coordinated the translation and pretest phase, executed data collection and analyses, and wrote the manuscript. H. Arwert created the initial study population and was closely involved in writing the manuscript. P. Goossens played an important role in the translation process and revised the manuscript. T. Vliet Vlieland advised on the study methodology and was closely involved in the translation process and writing the manuscript.

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1052-3057/\$ - see front matter

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<https://doi.org/10.1016/j.jstrokecerebrovasdis.2017.08.043>

## Introduction

Worldwide, stroke is one of the leading causes of death and disability.<sup>1</sup> Despite recent advances in stroke treatment, stroke can result in impairments in body functions, limitations in activities, and restrictions in participation<sup>2</sup> that often persist years after stroke.<sup>3</sup> 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.<sup>3</sup>

If expressed needs are not satisfied by their current service provision, they are classified as unmet.<sup>4</sup> Unmet needs are relevant because they are associated with reduced quality of life for both patients<sup>5</sup> and caregivers.<sup>6</sup> 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.<sup>7</sup> In the literature, the most frequently reported unmet need concerns information on the causes and prevention of stroke.<sup>3,8</sup> Other areas in which unmet needs are frequently reported include fatigue, memory, and emotion.<sup>9-11</sup> Regarding the unmet needs of Dutch stroke survivors, a multicenter study on the quality of care showed that 31% (N = 120) of noninstitutionalized 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.<sup>12</sup>

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.<sup>13</sup> Its content was based on a literature review and semistructured interviews with stroke survivors.<sup>14</sup> 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).<sup>13</sup>

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  $\geq 18$  years who had been admitted to the hospital for their first-ever stroke. That study was described in greater detail in a previous publication.<sup>15</sup> 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.<sup>16</sup> The validation process of the LUNS was conducted in accordance with the COnsensus-based Standards for the selection of health Measurement INstruments criteria.<sup>17</sup>

### *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.<sup>18</sup> 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.<sup>19</sup>

#### **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

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