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The Longer-Term Unmet Needs After Stroke Questionnaire: Cross-Cultural Adaptation, Reliability, and Validity for an Arabic Population

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Arab American University
Faculty of Graduate Studies
Department of Health Sciences
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Thesis Approval



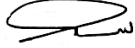
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Declaration

I declare that, except where explicit reference is made to the contribution of others, this thesis is substantially my own work and has not been submitted for any other degree at the Arab American University or any other institution.

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First, I give all the glory to God, the source of our strength, for granting us both the mental and physical endurance to complete this monumental task.

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Abstract

Background: An extended range of diverse types of unfulfilled needs often occur in the case of stroke, encompassing physical, emotional, and social domains. These unmet needs must be addressed to enhance survivors' quality of life. Unfortunately, there is no Arabic tool to evaluate the comprehensive needs of stroke patients, which would help in understanding and addressing these needs properly.

Objective: To achieve this, the study was designed to translate and validate the Longer-Term Unmet Needs after Stroke (LUNS) Questionnaire for Arabic-speaking survivors.

Methods: A multi-center cross-sectional study was carried out in four rehabilitation centers in the city of Ramallah and Al-Bireh, Palestine. A total sample of 80 stroke survivors at 5 to 8 years since the stroke event was included in the study using convenience sampling. The LUNS instrument was translated and culturally adapted in the process of the study using well-established guidelines. Its psychometric properties, including test-retest reliability and concurrent validity, were evaluated by comparison with the SF-12 Health Survey and the Frenchay Activities Index (FAI).

Results: The test-retest reliability analysis demonstrated moderate to substantial agreement (Cohen's Kappa coefficients between 0.45 and 0.67). Internal consistency reliability was high (Cronbach's alpha: 0.771–0.874). Concurrent validity analyses revealed significant associations between LUNS items and health-related measures in the expected directions. Some of the most frequently reported unmet needs in this study included the need for information about stroke (86.3%) and the need for medical checkups (62.5%).

Summary: A survey conducted in Arabic regarding the unmet needs of stroke survivors serves as a reliable tool for addressing research gaps in stroke rehabilitation science and its practical applications. It also facilitates the implementation of tailored interventions aimed at improving the quality of life for these individuals.

Keywords: LUNS, stroke, Arabic translation, psychometric validation, unmet needs.

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1. Introduction

1.1 Background

The WHO expert committee on cerebrovascular disease groups all cerebrovascular accidents under the term stroke (CVA). The World Health Organization defines stroke as the “rapidly developing clinical signs of focal disturbance of cerebral function, with symptoms lasting 24 hours or longer or leading to death.” Within this definition, the patient may exhibit a transient ischemic event. Stroke can occur due to a blockage (ischemic stroke) or a blood vessel bursting (hemorrhagic stroke), leading to cell death and deteriorating health functions. Stroke is one of the leading causes of disability and death worldwide (World Health Organization, 2021).

Health issues related to stroke may appear weeks, months, or even years after hospital discharge. Various long-term complications of stroke include post-stroke epilepsy, urinary and fecal incontinence, cognitive impairment, spasticity and hypertonicity, hemiplegic shoulder pain, wrist and finger flexor contractures, post-stroke depression, emotional lability, and mood disturbances (Chohan et al., 2019). If the needs articulated by patients during therapy are not met, the patients’ quality of life (QoL) is reduced. Unmet needs in addressing physical, psychological, and social issues can be a complex challenge for stroke survivors (Andrew et al., 2016).

Quality of life among stroke patients in the Arab world has been reported to be low. For example, a study in Kuwait found that 75% of stroke patients experienced a low quality of life; patients’ age, presence of children, comorbid conditions, and social status significantly influenced QoL (Mohammed, 2019). Similarly, research in Saudi Arabia reported that stroke patients had a poor quality of life primarily due to poor physical health (Alshahrani, 2020). These findings highlight the need for a reliable Arabic-language questionnaire to evaluate the long-term effects of stroke on mental, physical, and social well-being of stroke survivors and their families, which in turn could help maintain or improve the quality of life of both patients and family members.

Assessing long-term unmet needs after stroke is important because it captures the patient's perspective on psychological, physical, and social health post-stroke. In the Arabic context, valid and reliable measures to assess the long-term unmet needs of people post-stroke are lacking. To the best of our knowledge, no appropriate validated tool has been available to comprehensively assess the long-term needs of Arabic-speaking stroke survivors. In particular, the LUNS questionnaire had not yet been translated into Arabic or evaluated for its psychometric properties in an Arabic population.

1.2 Problem Statement

Quality of life for stroke survivors is described as the degree of well-being, self-satisfaction, and self-realization that stroke patients achieve in their lives. It includes physical, mental, and social dimensions, with sub-domains including bodily functions, emotional well-being, interpersonal relationships, and the impacts of stroke on neurological functions (Theofilou, 2013).

Stroke survivors often experience long-term unmet needs related to these physical, psychological, and social domains. If not addressed, these unmet needs can reduce treatment adherence and increase the risk of recurrent stroke (Gemmell et al., 2011; Xiao et al., 2018). A study in Saudi Arabia found that stroke survivors reported a low quality of life (Alshahrani, 2020), reflecting a gap in the continuity of post-stroke care for Arabic-speaking populations. However, there is currently no validated tool in Arabic to systematically assess these long-term unmet needs. The Longer-Term Unmet Needs after Stroke (LUNS) questionnaire is an established instrument used internationally for this purpose, but it has not yet been translated or validated for Arabic-speaking patients. Therefore, this study seeks to address this gap by translating, culturally adapting, and validating an Arabic version of the LUNS questionnaire to support better identification of unmet needs in this population.

1.3 Significance of the Study

This study addresses a significant shortcoming in stroke rehabilitation research by creating a culturally appropriate Arabic version of a questionnaire to measure the unmet needs of Arabic-speaking individuals with stroke. By accounting for cultural aspects in the Arab context, the adapted questionnaire will allow for better-targeted interventions and improved rehabilitation outcomes. This study also enables comparisons with findings from other populations regarding the long-term effects of stroke, thus assisting policymakers with the objective of improving stroke care and support in Arabic-speaking communities. The importance of this work lies in creating a valid tool specific to Arabic-speaking stroke survivors, which will help identify their unique needs and ultimately influence their well-being and quality of life.

1.4 Objectives of the Study

1. To conduct a cross-cultural adaptation of the Longer-Term Unmet Needs after Stroke (LUNS) Questionnaire into Arabic.
2. To examine the convergent validity of the Arabic LUNS by assessing its relationship with the Frenchay Activities Index (FAI) and the SF-12 Health Survey.
3. To evaluate the test-retest reliability of the translated Arabic version of LUNS.

1.5 Research Questions

1. Does the Arabic version of LUNS demonstrate good test-retest reliability among stroke survivors?
2. Does the Arabic version of LUNS demonstrate convergent validity, as evidenced by significant associations between LUNS scores and the Frenchay Activities Index and SF-12 measures?

2. Literature Review

A comprehensive literature search was conducted using databases such as MEDLINE, PubMed, Google Scholar, and EBSCO, with keywords including “stroke,” “CVA,” “cerebrovascular accident,” “longer-term unmet needs,” and “LUNS.”

2.1. Long-Term Impact of Stroke and the Emergence of Unmet Needs

Cerebrovascular events (strokes) cause damage to specific regions of the brain, often resulting in significant mortality, prolonged disability, and lasting neurological impairment (Hankey, 2017). Stroke arises from an interruption of blood supply to the brain, due to causes such as clots, emboli, or hemorrhage (Coupland et al., 2017). The two primary types are ischemic and hemorrhagic stroke, and transient ischemic attacks are minor strokes distinguished by symptom duration (Coupland et al., 2017).

Stroke is a major contributor to disability and mortality, ranking second globally in 2019 (Feigin et al., 2022). Over half of stroke survivors aged 65 or older have reduced mobility, making stroke a leading cause of long-term disability (Tsao et al., 2023). Beyond the acute phase, stroke profoundly impacts bodily functions, daily activities, and various aspects of life, affecting survivors’ performance skills and routines (Fox & Farus-Brown, 2019). Many survivors face enduring challenges that necessitate ongoing healthcare support for years post-stroke (Chohan et al., 2019). Long-term medical complications can include incontinence, cognitive impairment, spasticity, chronic pain, limb contractures, depression, emotional lability, and mood changes (Chohan et al., 2019). These impairments can limit survivors’ ability to perform basic life activities, such as eating, moving, self-care, and communication, and restrict their participation in social and community life (Rymer et al., 2013; Walker et al., 2013; Tuppin et al., 2014).

When formal rehabilitation ends and survivors’ transition back to home and community settings, many may not have adequate access to continued therapy, emotional support, or social integration opportunities. This gap can lead to unmet needs becoming apparent in the long-term post-stroke phase. Quick acute medical management may stabilize patients, but many continue to experience emotional, mental, and physical difficulties for years after stroke (Chen et al., 2019). Barriers such as limited individualized rehabilitation programs, inadequate mental health

services, and scarce community resources often result in suboptimal long-term recovery (Chen et al., 2019).

Unmet needs are defined as needs that remain unaddressed during the provision of rehabilitation services, including emotional, physical, and social needs (Crow, 2018). These needs encompass different aspects of patient well-being. The emotional domain refers to coping with psychological issues such as depression, anxiety, or frustration during recovery. The physical domain refers to ongoing physiological or functional needs, for example requiring mobility aids or medical management for stroke-related impairments (weakness, speech difficulties, coordination problems). The social domain involves the need for social interaction, family support, and community involvement, which are essential for holistic rehabilitation. Crow (2018) aimed to ensure that services meet these multiple needs by establishing comprehensive support systems, hoping to improve outcomes by addressing emotional, physical, and social requirements equally.

2.2 Common Unmet Needs Among Stroke Survivors

The needs of stroke survivors are diverse, ranging from medical care and therapy to social support and basic daily living assistance. These requirements are interrelated: physical rehabilitation, emotional recovery, and social participation all contribute to overall recovery. It is also recognized that different stakeholders may prioritize needs differently. For example, healthcare providers often emphasize medical and rehabilitation needs, whereas stroke survivors themselves may value emotional or social support more, as those are closely tied to their quality of life and long-term adjustment (Lin et al., 2021). This difference in perspective underlines the complexity of stroke recovery and the importance of a person-centered, holistic approach to meeting survivors' multidimensional needs (Lin et al., 2021).

Unmet needs can begin to manifest soon after the acute phase (within weeks or months after stroke) and may persist or even worsen over time. As patients move from hospital-based care to home or community settings, gaps in support become more evident. In the first year post-stroke, especially after formal rehabilitation services cease; survivors often have to manage the long-term effects of stroke on their own. Unmet needs, particularly in mental health, social

participation, and ongoing rehabilitation, can continue for years, highlighting the importance of long-term support for stroke survivors (Andrew et al., 2014).

Research has attempted to categorize these long-term needs. For instance, a qualitative synthesis of studies from eleven countries identified three broad themes of stroke survivors' needs (Krishnan et al., 2017):

- **Body Functions and Structures Needs:** including psychological, physical, and cognitive functions, and uncertainties related to these areas.
- **Activity and Participation Needs:** including healthy lifestyle maintenance, physical activity, speech and communication, independence in daily activities, cognitive engagement, and overcoming uncertainties in activities and participation.
- **Environmental Needs:** including the need for support services, safety, housing adaptations, accessibility, and dealing with uncertainties related to environmental factors.

This synthesis illustrates the complex and wide-ranging needs of stroke survivors and underscores that these needs are documented internationally across various countries (Krishnan et al., 2017).

Similarly, a narrative systematic review of articles (1990–2017) identified numerous categories of long-term unmet needs reported by stroke survivors and their caregivers (Zawawi et al., 2020). The most common unmet needs were psychosocial; such as support for depression, anxiety, social isolation, and help with adjustment, often exacerbated by limited service access and stigma. Informational and educational needs were also prominent; many survivors and caregivers lack information about stroke recovery, managing symptoms, and navigating the healthcare system. Social and community reintegration needs (support for resuming social activities, returning to work) highlight the difficulties survivors face in re-engaging with society (Zawawi et al., 2020).

Other unmet needs identified include:

- **Physical or Functional Needs:** Many survivors require ongoing therapy for mobility, help with activities of daily living, pain management, etc., which might be unavailable or unaffordable.
- **Cognitive and Communication Needs:** Rehabilitation for memory problems or speech difficulties often goes unmet due to lack of specialized services or insurance coverage.
- **Financial and Practical Needs:** Assistance with medical costs, transportation, and home modifications can strain families if support is insufficient.
- **Caregiver Needs:** Caregivers themselves often need training, respite care, and support, which are frequently unfulfilled.

Meeting this wide range of needs requires an organized, holistic stroke care system that supports survivors and caregivers throughout the long-term recovery journey (Zawawi et al., 2020).

The consequences of unmet needs are significant. Unaddressed needs can worsen the physical, emotional, and cognitive sequelae of stroke, leading to poorer rehabilitation outcomes, increased dependency, and reduced quality of life for stroke survivors. Unmet needs can contribute to mental health issues like depression or anxiety and can increase caregiver burden, as families may become overwhelmed by the lack of support, risking their own well-being and financial stability (Wellappuli et al., 2023). Identifying and addressing these needs is therefore crucial for patient-centered care.

2.3 Tools and Approaches for Assessing Unmet Needs

Properly assessing stroke survivors' unmet needs is essential for optimizing care and rehabilitation outcomes. Several tools and approaches have been developed to evaluate needs across physical, psychological, social, and cognitive domains:

- **Needs Assessment Questionnaire (NAQ):** A self-administered tool designed to measure stroke survivors' needs in physical, psychological, and social domains. It includes items on activities of daily living, emotional well-being, and social activities (Moreland et al., 2009). The NAQ is a brief measure of unmet physical, emotional, and social needs among stroke survivors. However, while useful, it provides a snapshot of

needs and may not capture the comprehensive longer-term picture that LUNS aims to address (Paschalidou et al., 2024).

- **Hospital Anxiety and Depression Scale (HADS):** Primarily a mood assessment tool for anxiety and depression, HADS can indicate unmet psychological needs if patients score high, signaling the need for mental health support (Rothwell et al., 2013).
- **WHO Quality of Life-BREF (WHOQOL-BREF):** A quality-of-life instrument covering physical health, psychological health, social relationships, and environment. It helps recognize domains where stroke survivors may have unmet needs by measuring their perceived health status (Rothwell et al., 2013).
- **Post-Stroke Checklist (PSC):** Developed by the World Stroke Organization, the PSC is administered by health workers during follow-ups to screen for common post-stroke problems across multiple domains (secondary prevention, cognition, mobility, activities of daily living, etc.) and thus identify any unmet needs requiring intervention (Rothwell et al., 2013).
- **Short Form-36 Health Survey (SF-36) or SF-12 Health Survey:** These health-related quality of life measures provide information on various health dimensions (physical functioning, pain, general health, vitality, social functioning, and mental health). Low scores in certain domains may signal unmet needs in those areas (Rothwell et al., 2013).
- **Frenchay Activities Index (FAI):** An instrument for instrumental activities of daily living and social activity levels. It reflects the level of activity and participation; lower scores could indicate unmet needs in community engagement or daily function (Schuling et al., 1993).
- **Rivermead Mobility Index (RMI):** Assesses mobility and physical ability in stroke patients. Poor mobility scores might highlight unmet needs in rehabilitation or assistive devices for physical functioning (Rothwell et al., 2013).

Each of these instruments focuses on specific aspects of a survivor's post-stroke life. They can help identify needs in their respective domains (e.g., mood, general health, mobility), but no single one of these provides a comprehensive assessment of long-term unmet needs across all domains. The LUNS questionnaire was developed to fill this gap by covering a broad range of life domains in one measure.

Only a few instruments worldwide have been specifically designed and psychometrically tested to measure the unmet needs of stroke survivors (Chen et al., 2019). One example is the **Stroke Needs Assessment Questionnaire (SNAQ)**, which consists of 77 questions and underwent initial validation (Kersten et al., 2002). The SNAQ had content validity established, but its discriminant validity was unclear and its predictive validity was only as expected for the population. Convergent validity was demonstrated (e.g., the number of unmet needs had no significant relationship with degree of disability, indicating it captured different information), and internal consistency was satisfactory. However, beyond internal consistency, further reliability statistics for SNAQ were not reported (Kersten et al., 2002).

Another approach was the **Self-Reported Long-Term Needs After Stroke** study, which developed a questionnaire based on a stroke register, with 44 closed questions covering information needs, health, daily living, work and leisure, relationships, support group use, finances, and demographics (McKevitt et al., 2011). While this tool was pilot-tested in the UK, and later adapted in Australia and Ireland (with 30-item and 58-item versions, respectively), none of these versions underwent thorough psychometric testing (Walsh et al., 2015).

2.4 The Longer-Term Unmet Needs after Stroke (LUNS) Questionnaire

The **Longer-Term Unmet Needs after Stroke (LUNS) Questionnaire** was explicitly developed to provide a comprehensive measure of long-term unmet needs of stroke survivors, spanning multiple life domains. The LUNS is a 22-item self-report instrument covering areas such as health information, communication problems, emotional health, mobility (walking ability), fatigue, cognition, social participation, and access to services (Rothwell et al., 2013). Each item addresses a specific potential need (for example, “Do you feel you need more information about stroke?” or “Do you have unmet needs regarding your mobility?”), and items are typically answered dichotomously (1 = unmet need, 0 = no unmet need). The total LUNS score is the sum of all items answered as unmet needs, with higher scores indicating a greater number of long-term needs that are not being met (Groeneveld et al., 2018).

The LUNS was originally developed in the United Kingdom through a rigorous process including a systematic literature search, qualitative interviews with stroke patients, and expert feedback to ensure the content was relevant and comprehensive (Rothwell et al., 2013). In its

initial validation study, Forster et al. (2013) administered the LUNS to 770 community-dwelling stroke survivors 3–6 months post-stroke in a two-phase study. They reported that unmet needs identified by LUNS were associated with worse outcomes on concurrent measures: patients with one or more unmet needs had significantly poorer health status on the General Health Questionnaire-12, the SF-12, and the FAI (Forster et al., 2013). Test-retest reliability of LUNS items in that study was moderate to good (Cohen’s κ ranging from 0.445 to 0.673 with agreement rates of 85.7%–95.8%), and internal consistency was good (Cronbach’s $\alpha = 0.815$) (Forster et al., 2014). These results indicated that LUNS is a stable and coherent tool for identifying post-stroke needs. While Forster et al. suggested that LUNS items might cluster into a few conceptual dimensions, they did not explicitly define subscales, treating LUNS as a unidimensional checklist of needs.

Since its introduction, the LUNS tool has been translated, culturally adapted, and validated in several countries and languages:

- **Netherlands:** The LUNS was adapted for Dutch stroke patients. In one validation study, 78 stroke survivors who were 5–8 years post-stroke were assessed; the median number of unmet needs was 3.5. Importantly, 15 of the 22 LUNS items showed significant associations with either the FAI or the SF-12 physical or mental component scores, supporting its concurrent validity in that context (Groeneveld et al., 2018).
- **France:** LUNS has been translated into French (Lévesque et al., 2020).
- **Brazil:** A Brazilian-Portuguese version was developed (Leal et al., 2020).
- **China:** A Chinese version was created (Yang et al., 2020).
- **Korea:** A Korean version was recently validated (Kim et al., 2021; Baek et al., 2023).
- **Malawi:** An adaptation into Chichewa (local language in Malawi) was conducted (Chinyani et al., 2021).

These international adaptations have generally demonstrated that the LUNS can be used reliably outside its original English context, with strong validity and reliability reported in the different cultural settings (Groeneveld et al., 2018; Kim et al., 2021; Baek et al., 2023). However, until now, LUNS had not been translated or validated for use in Arabic-speaking

populations, leaving a substantial gap in the availability of appropriate tools for these communities.

2.5 Summary of Gaps and Rationale for the Current Study

Although previous studies have greatly contributed to understanding stroke survivors' long-term unmet needs, there is a considerable knowledge gap concerning non-English speaking populations, particularly Arabic-speaking stroke survivors. Research such as Wellappuli et al. (2023) in Sri Lanka and Baek et al. (2023) in Korea have shown the importance of cultural adaptation and validation of the LUNS tool in different contexts. These studies highlight that language and culture can influence how stroke survivors perceive and report their needs. The Arabic language, with its many dialects and cultural nuances, may present unique challenges and differences in how needs are expressed and prioritized. Prior work has focused on English-speaking cohorts or translations in other languages, but no study to date has provided an Arabic version of the LUNS or evaluated its psychometric properties in an Arabic context.

In addition, many of the available studies on unmet needs were conducted in Western healthcare systems with different support structures. The way health services are organized, cultural attitudes toward disability and rehabilitation, and family roles in care can differ in Arabic countries. As a result, unmet needs identified in Western populations may not fully reflect the unmet needs of Arabic-speaking stroke survivors, who may face their own specific barriers to care, cultural stigmas, and levels of social support.

In summary, there is a clear need for an Arabic version of the LUNS and its validation:

- No Arabic instrument currently exists to comprehensively measure long-term post-stroke unmet needs.
- Without a validated tool, the magnitude and nature of unmet needs in Arabic-speaking stroke survivors remain understudied and potentially unaddressed.
- Validating the LUNS in Arabic will ensure that the tool is culturally and linguistically appropriate, preserving the content validity of the original while capturing nuances relevant to Arabic speakers.

The present study seeks to fill this gap by translating, culturally adapting, and testing the LUNS questionnaire for Arabic-speaking stroke survivors. By doing so, we aim to provide researchers and clinicians with a reliable and valid instrument to identify the longer-term unmet needs in this population, ultimately improving patient-centered care and informing the development of services and interventions tailored to Arabic-speaking communities.

3. Methodology

This chapter outlines the methodology of the study, including the study design, setting, participants, procedures for translation, data collection instruments, and data analysis strategies.

3.1 Study Design

The study is a multicenter cross-sectional study aimed at translating the LUNS questionnaire into Arabic and examining the psychometric properties of the Arabic version. All participants completed the Arabic LUNS once, and a subset completed it twice to allow assessment of test-retest reliability. The cross-sectional design is appropriate for the initial translation and cultural adaptation phase, enabling data collection from a diverse sample at one point in time. To evaluate test-retest reliability, a repeated-measures component was incorporated: a subset of participants was asked to complete the LUNS questionnaire a second time after a short interval. This approach ensured the study could assess both the tool's internal consistency and its stability over time (Olsen & St George, 2004).

3.2 Study Setting

The study was conducted in four rehabilitation centers in the Ramallah and Nablus, Jenin, and Bethlehem governorate of Palestine. These centers were chosen to capture a broad range of stroke survivors who receive follow-up care or therapy, thereby ensuring the sample included individuals with diverse backgrounds and experiences after stroke.

3.3 Study Population

The target population was stroke survivors in Palestine who continue to have rehabilitation needs years after their stroke. Participants were recruited from the outpatient departments of the rehabilitation centers.

3.4 Inclusion Criteria

Participants were eligible if they met the following criteria:

1. **Stroke survivors between 5 and 8 years post-stroke** who visit the rehabilitation center for follow-up or services.

2. Age 18 years or older.
3. Arabic-speaking, with the ability to understand the questionnaire (with assistance if they had minor communication difficulties).
4. Provided informed consent to participate.

3.5 Exclusion Criteria

Participants were excluded if they had:

- Significant cognitive impairment or communication deficits (e.g., severe aphasia or dementia) that precluded completing the questionnaire (determined via clinical judgment or medical records).
- Another significant neurological or psychiatric condition (aside from stroke) that could confound their responses about needs (e.g., major traumatic brain injury or severe mental illness).
- Participation in other overlapping intervention studies targeting post-stroke needs at the time of this study (to avoid confounding effects).

3.6 Sampling and Sample Size

A convenience sampling approach was used, recruiting all eligible and willing stroke survivors from the selected centers during the study period. The target sample size was calculated based on recommendations for validation studies. Using a sample size formula for correlation analyses (since validity would be assessed via correlations with other measures) and reliability testing, a minimum of 60 participants was deemed necessary to detect moderate correlations (around $r = 0.3-0.4$) with 80% power at $\alpha = 0.05$. To account for potential dropouts or unusable data, we aimed for approximately 80 participants. Indeed, 80 stroke survivors were successfully recruited and completed the study.

3.7 Period of the Study

The study took place from September 2023 to January 2024. This timeframe was selected to allow sufficient time for translation procedures, recruitment, administration of questionnaires (including re-tests for reliability), and data analysis within the academic schedule.

3.8 Translation Phase

The process of translation and cross-cultural adaptation of the LUNS followed the guidelines of Beaton et al. (2000), which consist of five structured stages:

Stage I: Forward Translation. Two forward translations of the original English LUNS into Arabic were produced by two independent bilingual translators whose mother tongue is Arabic. Translator 1 was a rehabilitation specialist (a physician and hospital director familiar with stroke care and the concepts in LUNS), ensuring understanding of the content. Translator 2 was a professional translator with no medical background and no prior exposure to the questionnaire. Using translators with different profiles (one medically informed, one naive to the content) helps reveal ambiguities or colloquialisms in the source text. Each translator produced a written Arabic version of LUNS.

Stage II: Synthesis. The two Arabic translations (T1 and T2) were then compared and synthesized into one combined version (T-12). A meeting was held with both translators and a recording observer. They reviewed each item from T1 and T2 alongside the original English version, discussed any discrepancies or differences in wording, and resolved any translation ambiguities. The observer documented the process, noting how disagreements were settled and ensuring that the synthesized translation retained the meaning of the original items while using clear and culturally appropriate Arabic phrasing.

Stage III: Back-Translation. The synthesized Arabic version (T-12) was back-translated into English by two new independent translators who were native English speakers with excellent Arabic proficiency. These back translators were blinded to the original LUNS questionnaire to avoid bias. One back-translator was the same specialist doctor (with English as a first language) and the other was a certified professional translator, both of whom had not seen the original English LUNS. They produced two back-translations (BT1 and BT2) of T-12 into English. This step checks for fidelity to the original content: if the back-translations closely match the original LUNS wording and intent, it suggests the Arabic version is accurate.

Stage IV: Expert Committee Review. An expert committee was convened, including the translators (forward and back), occupational therapists, a stroke rehabilitation specialist, and

a linguist. The committee reviewed all versions (T1, T2, T-12, BT1, BT2) and the original questionnaire to ensure semantic, idiomatic, experiential, and conceptual equivalence. In this review, each questionnaire item was scrutinized: the committee discussed whether the Arabic wording conveyed the same concept as the English, whether it was culturally appropriate, and whether any alternative phrasing might improve clarity. They then consolidated the translations to produce a pre-final Arabic version of LUNS ready for field testing. This version incorporated the committee's decisions on the best wording for each item.

Stage V: Test of the Pre-final Version (Pilot Testing). The pre-final Arabic LUNS was pilot-tested on 20 stroke survivors to assess its clarity, relevance, and cultural appropriateness. These pilots were conducted via interviews in two locations: 10 participants at Al-Amal Rehabilitation Center in Nablus and 10 at Khalil Abu Raya Rehabilitation Center in Ramallah. Participants completed the questionnaire and were asked for feedback on any item that was confusing or not applicable. This step ensured the questions were understandable and interpreted as intended. The participants' feedback was used to make minor adjustments to wording or format as needed. Feedback from the pilot indicated that the questionnaire was generally clear; only minor phrasing adjustments were required for a few items to improve clarity. These adjustments were made, resulting in the finalized Arabic version of the LUNS questionnaire (Appendix B).

Overall, cross-cultural adaptation is a process of translating and adjusting assessment tools for use in new languages or cultures while retaining the original meaning and measurement properties. We carefully followed this process to maintain both the reliability (the degree to which the instrument yields consistent results) and the validity (the degree to which it measures what it is intended to measure) of the LUNS in the Arabic context (Guillemin et al., 1993). Quality control measures were integral throughout the adaptation to preserve conceptual equivalence between the Arabic LUNS and the original English version.

3.9 Validity and Reliability

In this study, the psychometric evaluation of the new Arabic LUNS focused on its reliability and validity. To assess test-retest reliability, a subset of participants ($n = 20$) completed the Arabic LUNS twice, approximately two weeks apart. Given the dichotomous

(yes/no) nature of LUNS items, we used Cohen's kappa coefficient to evaluate agreement for each individual item between the two administrations. Kappa values were interpreted using standard benchmarks (e.g., values ≥ 0.75 indicating excellent agreement). We also computed the intraclass correlation coefficient (ICC) (two-way mixed-effects model, single measures) for the total LUNS score across the two time points to measure the overall stability of the instrument. An ICC closer to 1 indicates higher stability, with values ≥ 0.75 considered good and ≥ 0.90 considered excellent (Koo & Li, 2016).

To examine construct validity, we focused on convergent validity (sometimes also viewed as a form of concurrent validity in this context). We hypothesized that higher unmet needs (higher LUNS scores) would correlate with poorer quality of life and lower functional activity. Thus, we assessed correlations between the total LUNS score and scores on two established outcome measures: the SF-12 Health Survey and the Frenchay Activities Index (FAI). Spearman's rank correlation (Spearman's ρ) was used for these associations because the LUNS total is essentially an ordinal count of needs and the SF-12 and FAI scores are not guaranteed to be normally distributed. We expected negative correlations: for instance, individuals with more unmet needs (high LUNS score) would likely have lower SF-12 Physical and Mental Component Summary scores and lower FAI scores (indicating lower activity levels). A significant monotonic correlation in the hypothesized direction would support the convergent validity of the Arabic LUNS.

Internal consistency of the Arabic LUNS was evaluated using Cronbach's alpha to determine how well the items that make up the LUNS are inter-related as a single scale. A Cronbach's α of ≥ 0.70 was considered acceptable, with higher values indicating greater reliability of the scale in measuring the underlying construct of "unmet needs."

It is worth noting that the FAI and SF-12 measures employed for validation are themselves standardized instruments that have been adapted for Arabic populations. The FAI has an Arabic version with demonstrated reliability and validity in an Arabic-speaking sample (Al-Emran et al., 2020), and the SF-12 has been validated in Arabic with good psychometric properties (Haddad et al., 2021). This ensures that any correlations observed between LUNS and

these measures are interpretable and not confounded by translation issues in the comparator instruments.

3.10 Data Collection Instruments and Measures

3.10.1 Demographic and Medical Information

A short questionnaire was used to collect demographic and clinical information, including: gender, age at the time of stroke, education level, type of stroke (ischemic or hemorrhagic), stroke location (e.g., left or right hemisphere), whether the patient received thrombolytic therapy, and the duration of initial hospital treatment. This information provides context about the participant group and is presented in the results to describe the sample (see Table 4.1 and 4.2).

3.10.2 Standardized Outcome Measures

- 1. Frenchay Activities Index (FAI):** The FAI measures instrumental activities of daily living (IADL) and social activities, reflecting a person's level of activity and participation. It consists of 15 items (originally 10 items covering the past 3 months and 5 items covering the last 6 months). Each item is scored on a 4-point scale indicating how often the activity is performed (0 = never, 1 = rarely, 2 = sometimes, 3 = often). The total FAI score ranges from 0 (least active) to 45 (most active), with common interpretations being: 0–15 = inactive, 16–30 = moderately active, 31–45 = very active (Schuling et al., 1993). The FAI has been translated and culturally adapted into Arabic, showing good reliability and validity for use with Arabic-speaking patients (Al-Emran et al., 2020). This made it suitable as a comparator in our validity analysis.
- 2. 12-Item Short Form Health Survey (SF-12):** The SF-12 is a widely used health-related quality of life questionnaire derived from the SF-36. It has 12 questions that produce two composite scores: the Physical Component Summary (PCS) and the Mental Component Summary (MCS). Each SF-12 item has between 2 and 5 response options (for example, yes/no for some items, or frequency scales for others). The SF-12 yields scores for PCS and MCS that are typically norm-based (mean of 50, SD of 10 in reference populations), with higher scores indicating better health status. The SF-12 used in this study was the Arabic version, which has been previously translated and validated for Arabic-speaking

populations (Haddad et al., 2021). The availability of a valid Arabic SF-12 allowed us to use it to assess the construct validity (convergent validity) of LUNS. Specifically, we anticipated that individuals with more unmet needs would have lower SF-12 scores, reflecting poorer health-related quality of life.

3. **Longer-Term Unmet Needs after Stroke (LUNS) Questionnaire:** The LUNS, as described earlier, is a 22-item checklist covering different domains (physical, cognitive, emotional, and social needs). Each item is answered “Yes” (indicating an unmet need in that area) or “No” (need met or not applicable). The total number of “Yes” responses constitutes the overall unmet needs score (0 to 22). Key domains addressed include mobility problems, pain management, memory or thinking issues, mood/emotional support, occupational or vocational needs, informational needs about stroke, and social participation issues, among others. In this study, we used the newly translated Arabic version of the LUNS (see Appendix B), developed through the process detailed in section 3.8. The Arabic LUNS has the same structure and content as the original English version, but with language and examples adapted for cultural relevance. Participants self-reported their unmet needs by responding to each item in Arabic.

These instruments (FAI, SF-12, and LUNS) were administered in an interview format or self-completed by the participants, depending on their preference and abilities. Trained occupational therapy graduate students assisted participants who had difficulty reading or writing due to physical impairments (e.g., hemiplegia) or mild aphasia, by reading questions aloud and recording responses. Participants were encouraged to answer honestly and were assured that their responses would be kept confidential and used only for research purposes.

3.11 Statistical Analysis

All data were analyzed using IBM SPSS Statistics version 23 (Arkkelin, 2014). Descriptive statistics (mean, standard deviation for continuous variables; frequencies and percentages for categorical variables) were used to summarize participants’ demographic and clinical characteristics (e.g., age, gender, education, stroke type).

To evaluate the reliability of the Arabic LUNS, we performed test-retest analysis and internal consistency analysis. Cohen's kappa coefficients were calculated for each LUNS item to determine agreement between the first and second administration for the subset of participants who completed the questionnaire twice. In addition, the intraclass correlation coefficient (ICC) was computed for the total LUNS score across the two time points, providing an overall measure of test-retest reliability for the scale as a whole. We interpreted kappa and ICC values according to conventional standards (Landis & Koch, 1977; Koo & Li, 2016). Cronbach's alpha was calculated to assess the internal consistency of the LUNS, indicating how well the set of 22 items measures the unified construct of "unmet needs."

For validity, we examined convergent validity by calculating Spearman's rank correlation coefficients between the LUNS total score and the scores of the SF-12 (PCS and MCS) and the FAI. Spearman's rho was chosen due to the ordinal nature of some data and non-normal distributions. A negative Spearman correlation was expected (and tested) between LUNS and the other measures, since a higher number of unmet needs should be associated with lower quality of life (SF-12) and lower activity levels (FAI). We categorized the strength of correlations as weak, moderate, or strong based on absolute value (e.g., $|\rho| \sim 0.1$ weak, ~ 0.3 moderate, ~ 0.5 or above strong) to aid interpretation (Mukaka, 2012). The statistical significance threshold was set at $p < 0.05$ (two-tailed) for all analyses.

All statistical tests were organized and reported according to the aspects of psychometric evaluation: first, reliability (test-retest and internal consistency) and second, validity (convergent validity with SF-12 and FAI). No corrections for multiple comparisons were applied given the exploratory nature of this validation study; however, primary hypotheses (correlation of LUNS with SF-12 and FAI) were limited in number. The results are presented in Chapter 4 with tables summarizing key findings (demographics in Table 4.1 and 4.2, SF-12 responses in Table 4.3, FAI responses in Table 4.4, LUNS item responses in Table 4.5, test-retest statistics in Table 4.6, and validity correlations in Table 4.7 and 4.8).

3.12 Ethical Considerations

The study was approved by the Institutional Review Board (IRB) at Arab American University (see Appendix A for the IRB approval letter). All procedures were conducted in

accordance with the ethical standards of the university's research committee and the 1964 Helsinki declaration and its later amendments.

Participants were provided with detailed information about the study in plain Arabic language, and written informed consent was obtained from each participant (or a legal guardian when appropriate) before data collection. Participation was entirely voluntary, and participants were free to refuse or withdraw at any time without any effect on the services they received at the center.

Confidentiality of participants' data was strictly maintained: each participant was assigned a code, and no personally identifying information was included in the data analysis. Completed questionnaires and consent forms were stored securely in a locked cabinet accessible only to the research team, and electronic data were kept on a password-protected computer.

Permission to use and translate the LUNS questionnaire was obtained from the original developers of the tool via email prior to beginning the study. This ensured respect for intellectual property rights and allowed for collaboration if needed.

The study posed minimal risk to participants. Aside from the time spent answering questionnaires, there were no interventions or changes to their treatment. Some participants might have experienced mild emotional discomfort when reflecting on unmet needs or challenges since their stroke. To address this, the researchers were prepared to provide brief supportive counseling and refer participants to appropriate services (psychologist, social worker, or physician) if any significant distress or previously unidentified need arose during the interview.

In summary, all necessary steps were taken to ensure the study was ethical, with respect for participants' autonomy, privacy, and well-being throughout the research process.

4. Results

This chapter presents the findings of the study in a structured manner. First, the demographic and clinical characteristics of the participant cohort are described. Second, the responses on the outcome measures used for validity (the SF-12 Health Survey and the Frenchay Activities Index) are summarized. Third, the prevalence of unmet needs as identified by each item of the LUNS questionnaire is reported. Finally, the psychometric properties of the Arabic LUNS are detailed, including test-retest reliability and validity (correlation) results.

4.1 Demographic and Clinical Characteristics

A total of 80 stroke survivors participated in this study. The sample had a mean age of 49.78 years (SD = 10.61) at the time of their stroke. The cohort was predominantly male (60.0%, n = 48). In terms of education, a majority of participants (61.3%, n = 49) held at least a bachelor's degree, while the rest had primary or secondary school education. Regarding stroke type, ischemic strokes were more common (70.0%, n = 56) than hemorrhagic strokes (30.0%, n = 24). Most participants had a right hemisphere lesion (66.3%, n = 53), with the remainder having left hemisphere involvement. A large proportion (80.0%, n = 64) of participants reported having received thrombolytic therapy during their acute stroke treatment.

All participants were between 5 and 8 years post-stroke at the time of data collection, as per the inclusion criteria. The duration of initial hospital treatment (acute care and any inpatient rehabilitation) varied widely, ranging from 7 days to 1000 days (about 2.7 years) with an average of 184.0 days (SD = 204.1). This variability reflects differing stroke severities and healthcare circumstances among the participants.

(Tables 4.1 and 4.2 present the detailed demographic and clinical characteristics of the participants.)

Table 4.1: Demographic Characteristics of the Participants (N = 80)

(This table shows the distribution of participants by gender and education level.)

Variable	Category	Frequency n (%)
Gender	Male	48 (60.0)
	Female	32 (40.0)
Level of Education	Primary school	8 (10.0)
	Secondary school	23 (28.8)
	Bachelor degree	49 (61.3)
Type of CVA	Ischemic CVA	56 (70.0)
	Hemorrhagic stroke	24 (30.0)
CVA Site	Right hemisphere	53 (66.3)
	Left hemisphere	27 (33.8)
Received Thrombolysis	No	16 (20.0)
	Yes	64 (80.0)

Table 4.2: Clinical Characteristics of the Participants (N = 80)

(This table shows stroke type, stroke hemisphere, thrombolysis received, and descriptive statistics for age and hospital stay duration.)

Variable	Minimum	Maximum	Mean	Std. Deviation
Age at time of CVA (years)	28.00	78.00	49.78	10.61
Period of treatment in hospital (days)	7.00	1000.00	184.04	204.13

4.2 Health-Related Quality of Life and Functional Activity Levels

Participants' health status and functional abilities were assessed using the Arabic SF-12 and the FAI, respectively.

SF-12 Results: Table 4.3 summarizes responses to the SF-12 items. Notably, only one-third of participants (33.8%, n = 27) rated their general health as “Good,” with none rating it “Excellent” (the remainder rated it “Fair” or “Poor”), indicating generally low self-perceived health. A majority of participants reported limitations in physical activities: 65.0% (n = 52) had at least some difficulty with moderate activities (like moving a table or pushing a vacuum cleaner), and 68.8% (n = 55) had difficulty climbing several flights of stairs. Between 75% and 89% of participants indicated that physical health or emotional problems caused them to accomplish less than they would like or to do activities less carefully than usual, reflecting substantial functional and role limitations. Pain was also an issue for over half of the group: 53.8% (n = 43) said pain interfered with their normal work (including both work outside the home and housework) to a moderate extent (or more). On the mental health side, 46.3% (n = 37) reported feeling low energy or easily fatigued “some of the time,” and 35.0% (n = 28) felt downhearted and depressed “a good bit of the time.” These findings indicate that years after their stroke, many participants still experience significant physical and emotional challenges that affect their daily lives.

FAI Results: The FAI responses (detailed in Table 4.4) demonstrated restricted participation in instrumental activities of daily living and social activities. High proportions of participants reported never performing certain tasks that are common in independent living. For example, 53.8% (n = 43) never washed clothing, 47.5% (n = 38) never did heavy housework, and 43.8% (n = 35) never prepared a main meal – possibly indicating reliance on caregivers or family for these tasks. In terms of community and social engagement, 66.3% (n = 53) said they attended social outings (such as parties, club meetings, or religious gatherings) only “1–2 times in 3 months,” and 42.5% (n = 34) reported never driving or taking public transport (bus). The overall activity levels were low; indeed, based on the total FAI scores, a substantial segment of the sample would be classified as “inactive.” These results suggest that many participants remain limited in community reintegration and daily activity engagement long after their stroke.

Table 4.3: provide item-level response frequencies for the SF-12 Health Survey respectively

Item	Response	Frequency n (%)
In general, would you say your health is:	Poor	4 (5.0)
	Fair	22 (27.5)
	Good	27 (33.8)
	Very good	23 (28.8)
	Excellent	4 (5.0)
Moderate activities:	No, not limited at all	10 (12.5)
	Yes, limited a little	52 (65.0)
	Yes, limited a lot	18 (22.5)
Climbing several flights of stairs:	No, not limited at all	10 (12.5)
	Yes, limited a little	55 (68.8)
	Yes, limited a lot	15 (18.8)
Accomplished less than you would like:	No	20 (25.0)
	Yes	60 (75.0)
Were limited in the kind of work or other activities:	No	14 (17.5)
	Yes	66 (82.5)
Accomplished less than you would like (emotional):	No	19 (23.8)
	Yes	61 (76.3)
Did work or activities less carefully than usual:	No	9 (11.3)
	Yes	71 (88.8)
How much did pain interfere with normal work:	Not at all	6 (7.5)
	A little bit	21 (26.3)
	Moderately	43 (53.8)
	Quite a bit	9 (11.3)
	Extremely	1 (1.3)
Have you felt calm and peaceful?	None of the time	2 (2.5)
	A little of the time	15 (18.8)
	Some of the time	30 (37.5)
	A good bit of the time	18 (22.5)
	Most of the time	12 (15.0)
	All of the time	3 (3.8)
Did you have a lot of energy?	None of the time	1 (1.3)
	A little of the time	24 (30.0)
	Some of the time	37 (46.3)
	A good bit of the time	9 (11.3)
	Most of the time	8 (10.0)
	All of the time	1 (1.3)
Have you felt downhearted and blue?	A little of the time	15 (18.8)
	Some of the time	22 (27.5)

	A good bit of the time	28 (35.0)
	Most of the time	13 (16.3)
	All of the time	2 (2.5)
Physical/emotional problems interfered with social activities:	None of the time	15 (18.8)
	A little of the time	37 (46.3)
	Some of the time	4 (5.0)
	Most of the time	18 (22.5)
	All of the time	6 (7.5)

Table 4.4: provide item-level response frequencies for the Frenchay Activities Index (FAI) respectively

Item	Response	Frequency n (%)
Preparing main meals	Never	35 (43.8)
	Less than once a week	18 (22.5)
	1-2 times per week	17 (21.3)
	Most days	10 (12.5)
Washing up after meals	Never	29 (36.3)
	Less than once a week	23 (28.8)
	1-2 times per week	16 (20.0)
	Most days	12 (15.0)
Light housework	Never	28 (35.0)
	1-2 times in 3 months	32 (40.0)
	3-12 times in 3 months	8 (10.0)
	At least weekly	12 (15.0)
Heavy housework	Never	38 (47.5)
	1-2 times in 3 months	28 (35.0)
	3-12 times in 3 months	8 (10.0)
	At least weekly	6 (7.5)
Washing clothes	Never	43 (53.8)
	1-2 times in 3 months	20 (25.0)
	3-12 times in 3 months	5 (6.3)
	At least weekly	12 (15.0)

Local Shopping	Never	19 (23.8)
	1-2 times in 3 months	25 (31.3)
	3-12 times in 3 months	28 (35.0)
	At least weekly	8 (10.0)
Social occasions	Never	16 (20.0)
	1-2 times in 3 months	53 (66.3)
	At least weekly	11 (13.8)
Walking outside for >15 minutes	Never	14 (17.5)
	1-2 times in 3 months	35 (43.8)
	3-12 times in 3 months	15 (18.8)
	At least weekly	16 (20.0)
Actively pursuing hobby	Never	29 (36.3)
	1-2 times in 3 months	31 (38.8)
	3-12 times in 3 months	10 (12.5)
	At least weekly	10 (12.5)
Driving car/going on bus	Never	34 (42.5)
	1-2 times in 3 months	19 (23.8)
	3-12 times in 3 months	12 (15.0)
	At least weekly	15 (18.8)
Travel outing/car ride	Never	14 (17.5)
	1-2 times in 6 months	21 (26.3)
	3-12 times in 6 months	32 (40.0)
	At least weekly	13 (16.3)
Gardening	Never	42 (52.5)
	Light	27 (33.8)
	Moderate	9 (11.3)
	Heavy/All necessary	2 (2.5)
Reading books	None	25 (31.3)
	1 in 6 months	22 (27.5)
	Less than 1 in 2 weeks	14 (17.5)
	More than 1 every 2 weeks	19 (23.8)

Gainful work	None	37 (46.3)
	Up to 10 hours/week	23 (28.8)
	10-30 hours/week	12 (15.0)
	Over 30 hours/week	8 (10.0)

4.3 Unmet Needs Identified by the LUNS Questionnaire

All 80 participants completed the Arabic LUNS questionnaire, indicating whether or not they had unmet needs in each of 22 areas. Table 4.5 shows the percentage of participants who reported an unmet need for each LUNS item. The following were among the most frequently reported unmet needs:

- **Need for information about stroke:** 86.3% (n = 69) of participants responded that they still needed more information about stroke, its consequences, or management. This was the highest endorsed item, highlighting a major gap in patient education and information provision.
- **Need for medical check-ups or follow-up:** 62.5% (n = 50) indicated they had unmet needs regarding ongoing medical check-ups, suggesting that regular follow-up or access to healthcare post-stroke might not be sufficient.
- **Emotional support needs:** Over half of the participants (55%, n = 44) reported unmet needs related to mood or emotional well-being (for example, dealing with feelings of depression, anxiety, or frustration).
- **Physical therapy/exercise needs:** Approximately 50% (n = 40) had unmet needs in continuing physical rehabilitation or exercise guidance.
- **Social and leisure activities:** 48.8% (n = 39) indicated unmet needs in participating in social or leisure activities, consistent with the low activity levels seen in the FAI results.
- **Mobility and transportation:** 46.3% (n = 37) reported an unmet need related to mobility (such as difficulties getting around) or transportation support.
- **Activities of daily living:** Needs such as help with personal care or housework were noted by about 40% of participants as unmet.

On the other hand, some areas were less commonly reported as unmet needs:

- **Financial support:** Only 22.5% (n = 18) indicated unmet financial needs (like needing financial advice or support due to their condition), possibly reflecting that many had family support or stable arrangements.
- **Communication:** 20.0% (n = 16) had unmet needs regarding communication problems (e.g., speech difficulties or understanding others).
- **Intimate relationships/sex life:** 18.8% (n = 15) reported unmet needs in this area, although it's possible some participants were not comfortable discussing or might have skipped this item.

In total, LUNS scores (the count of unmet needs) ranged widely among participants. The median number of unmet needs was 7 (with an interquartile range of approximately 5 to 10). This indicates that a typical participant still had around seven long-term needs unmet years after their stroke. Only 5% of participants reported no unmet needs at all, whereas at the other extreme, about 10% of participants checked “Yes” for more than 15 out of 22 needs, suggesting a subset of survivors with very high levels of unmet needs across the board.

These results highlight that even 5–8 years post-stroke, survivors in this sample have multiple areas where their needs are not fully addressed. This breadth of unmet needs spans medical, rehabilitative, informational, emotional, and social domains, reinforcing the importance of comprehensive long-term support for stroke survivors.

Table 4.5: lists each LUNS need item and the percentage of participants reporting it as unmet

LUNS Item	Answer	Frequency n (%)
LUNS1: I would like more information about my stroke.	No	11 (13.8)
	Yes	69 (86.3)
LUNS2: I would like a medication/blood pressure check-up.	No	30 (37.5)
	Yes	50 (62.5)
LUNS3: I regularly get pain and nothing seems to ease it.	No	46 (57.5)
	Yes	34 (42.5)
LUNS4: My walking/moving is getting worse with no help.	No	42 (52.5)

	Yes	38 (47.5)
LUNS5: I am worried about falling.	No	14 (17.5)
	Yes	66 (82.5)
LUNS6: I need additional aids or adaptations inside the home.	No	21 (26.3)
	Yes	59 (73.8)
LUNS7: I need adaptations outside the home.	No	17 (21.3)
	Yes	63 (78.8)
LUNS8: I need help/advice about driving/getting a blue badge.	No	27 (33.8)
	Yes	53 (66.3)
LUNS9: I would like to find out about travelling on public transport.	No	29 (36.3)
	Yes	51 (63.8)
LUNS10: I would like outside help to get jobs done in my home.	No	21 (26.3)
	Yes	59 (73.8)
LUNS11: I would like to look into options for moving to another home.	No	33 (41.3)
	Yes	47 (58.8)
LUNS12: I would like some advice about how to improve my diet.	No	12 (15.0)
	Yes	68 (85.0)
LUNS13: I need advice to help me manage my money better.	No	31 (38.8)
	Yes	49 (61.3)
LUNS14: I would like help to find out about, or to apply for, benefits.	No	16 (20.0)
	Yes	64 (80.0)
LUNS15: I would like advice on employment after stroke.	No	14 (17.5)
	Yes	66 (82.5)
LUNS16: I need more help with things like cutting my toenails, washing myself, or dental care.	No	32 (40.0)
	Yes	48 (60.0)
LUNS17: I have problems with my bladder/bowel and would like some help.	No	43 (53.8)
	Yes	37 (46.3)
LUNS18: I am concerned about my physical relationship with my partner and would like advice.	No	37 (46.3)
	Yes	43 (53.8)
	No	32 (40.0)

LUNS19: I forget things or find it hard to concentrate and would like help.	Yes	48 (60.0)
LUNS20: I often feel quite low, angry or worried and would like to find out what help is available.	No	16 (20.0)
	Yes	64 (80.0)
LUNS21: I would like to occupy my day better but don't know how.	No	16 (20.0)
	Yes	64 (80.0)
LUNS22: I would like to find out about holidays/breaks that cater for people with disabilities.	No	22 (27.5)
	Yes	58 (72.5)

4.4 Psychometric Properties of the Arabic LUNS

4.4.1. Test-Retest Reliability

Out of the 80 participants, 20 participants were able to complete the LUNS questionnaire a second time within approximately a two-week interval. This subgroup was used to examine test-retest reliability.

Cohen's kappa was calculated for each of the 22 LUNS items to measure agreement between the first and second administrations. The kappa values ranged from 0.45 to 0.67 across items. According to Landis and Koch (1977), this indicates moderate agreement for some items (κ in the 0.41–0.60 range) and substantial agreement for others (κ in the 0.61–0.80 range). None of the items fell below the 0.40 threshold (which would indicate only fair or slight agreement), and a few items approached the upper 0.6s. For example, the item regarding needing information about stroke had a kappa of around 0.67, suggesting that participants consistently answered that item the same way on both occasions. Items like needing help with mood/emotions or needing more therapy had kappa values in the 0.5–0.6 range, indicating moderate reliability, which is acceptable for this type of yes/no self-report data, given that some change or fluctuation in perceived needs over two weeks is plausible.

In addition to item-level agreement, we evaluated the stability of the overall LUNS score. The intraclass correlation coefficient (ICC) for the total LUNS score between the two time points was 0.85 (95% confidence interval approximately 0.70–0.93). This high ICC suggests excellent

test-retest reliability for the total count of unmet needs. In practical terms, participants who reported a high number of needs in the first administration tended to report a similarly high number in the second administration. This consistency indicates that the Arabic LUNS yields stable results over a short-term period when no major interventions or life changes have occurred in between.

Table 4.6: presents the test-retest reliability statistics: kappa for each item and the ICC for the total score

LUNS Item	T1 Yes% (n=41)	T2 Yes% (n=41)	% Agreement	Kappa (κ)	p-value
LUNS1	86.3%	84.2%	98.0%	0.41	.012
LUNS2	62.5%	50.0%	87.5%	0.45	.004
LUNS3	51.3%	38.5%	87.2%	0.65	<.001
LUNS4	42.5%	47.5%	95.0%	0.60	<.001
LUNS5	73.8%	70.0%	96.3%	0.43	.006
LUNS6	65.0%	56.1%	91.1%	0.90	<.001
LUNS7	70.0%	71.0%	99.0%	0.46	.003
LUNS8	58.8%	64.1%	94.6%	0.35	.027
LUNS9	55.0%	71.8%	83.2%	0.44	.002
LUNS10	66.3%	77.5%	88.8%	0.42	.006
LUNS11	52.5%	53.8%	98.7%	0.54	.001
LUNS12	77.5%	62.5%	85.0%	0.32	.035
LUNS13	55.0%	47.4%	92.4%	0.47	.004
LUNS14	72.5%	64.1%	91.6%	0.64	<.001
LUNS15	82.5%	70.3%	87.8%	0.54	<.001
LUNS16	55.0%	44.7%	89.7%	0.52	.001
LUNS17	45.0%	52.6%	92.4%	0.37	.019
LUNS18	53.8%	40.0%	86.3%	0.51	.001
LUNS19	60.0%	55.0%	95.0%	0.59	<.001
LUNS20	80.0%	82.5%	97.5%	0.92	<.001
LUNS21	80.0%	61.0%	81.0%	0.24	.045

LUNS22	72.5%	61.0%	88.5%	0.62	<.001
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Note: Weighted Kappa test was used.

4.4.2. Convergent Validity (Associations with SF-12 and FAI)

To evaluate the convergent validity of the Arabic LUNS, we examined its associations with the SF-12 and FAI scores. Spearman’s rank correlation was used to calculate the correlation coefficients, given the ordinal nature of some variables and non-normal distributions.

- **LUNS and FAI:** We found a significant negative correlation between the total LUNS score and the FAI score ($\rho = -0.32, p < 0.01$). This indicates that participants with more unmet needs tended to have lower activity levels (as measured by FAI). The magnitude of this correlation is in the moderate range. It aligns with our expectation: unmet needs likely include things related to mobility, self-care, or social activities, which would be reflected in a lower FAI (indicating fewer activities performed).
- **LUNS and SF-12 (Physical Component Score, PCS):** There was a negative correlation between LUNS score and the SF-12 Physical Component Summary (PCS) score ($\rho = -0.22, p < 0.05$). This correlation, while statistically significant, is weaker. It suggests that those with more unmet needs also reported somewhat poorer physical health status. The weaker magnitude could be due to the PCS encompassing aspects (like pain or general health perceptions) that are not directly one-to-one with the needs listed in LUNS. Nonetheless, the direction supports convergent validity.
- **LUNS and SF-12 (Mental Component Score, MCS):** Notably, the correlation between LUNS score and the SF-12 Mental Component Summary (MCS) was stronger and also negative ($\rho = -0.52, p < 0.01$). This is a moderately strong correlation, indicating that a higher number of unmet needs is associated with significantly poorer mental health-related quality of life. Many LUNS items pertain to emotional and social support needs, which likely explains the stronger relationship with MCS. Participants who, for example, lack needed emotional support or social engagement (unmet needs captured by LUNS) also tend to rate their mental health and emotional role functioning lower on the SF-12.

To further explore these relationships, we also looked at item-level correlations between each LUNS item (coded 0/1) and the outcome measures (SF-12 PCS, SF-12 MCS, and FAI). Table 4.8 summarizes these correlations. Several illustrative findings:

- Unmet need in “**Having someone to talk to about your problems or feelings**” (a LUNS item related to emotional support) showed a significant positive correlation with SF-12 MCS ($\rho = +0.36$, $p < 0.01$ when coded appropriately), meaning those who said “Yes” to needing emotional support tended to have lower MCS scores (indicating worse mental health QoL).
- Unmet need in **personal care or self-care** (LUNS item) correlated with the FAI ($\rho = -0.33$ to -0.49 for related items, $p < 0.01$), indicating those needing help in daily living tasks had lower FAI scores.
- Unmet needs regarding **mobility (walking)** and **fear of falling** (LUNS items) were negatively correlated with FAI scores (e.g., $\rho = -0.31$ to -0.32 , $p < 0.01$), reflecting that participants who struggle with mobility or have not received enough help for it are indeed less active.

These item-level findings reinforce that the LUNS is capturing relevant problems that translate into measurable differences in quality of life and activity.

Overall, the pattern of correlations provides evidence for the convergent validity of the Arabic LUNS. The questionnaire’s scores correlate in a logical way with other measures of health status:

- More unmet needs → worse functional status (lower FAI).
- More unmet needs → worse physical health perception (lower SF-12 PCS).
- More unmet needs → worse mental health status (lower SF-12 MCS).

All correlations were in the expected direction and statistically significant. Table 4.7 may show comparisons of SF-12 and FAI scores between those with and without certain unmet needs. Table 4.8 lists Spearman’s rho values for correlations between each LUNS item and the outcomes.

Table 4.7: present the details of the validity analysis.

LUNS	Group	MCS	PCS	FAI
Item		Median (IQR)	Median (IQR)	Median (IQR)
LUNS1	No Unmet Need	53.89 (40.6-57.2)	52.22 (48.9-57.8)	58.33 (51.7-66.7)
	Unmet Need	53.89 (47.8-60.6)	52.78 (47.2-58.3)	48.33 (38.3-61.7)
LUNS2	No Unmet Need	53.89 (43.3-59.4)	52.50 (46.7-57.2)	55.00 (45.0-63.3)
	Unmet Need	55.83 (48.9-60.6)	52.78 (48.9-59.4)	50.00 (38.3-61.7)
LUNS3	No Unmet Need	53.33 (45.6-57.2)	51.94 (47.2-57.2)	55.00 (43.3-66.7)
	Unmet Need	57.22 (52.2-62.8)	53.61 (50.0-60.0)	44.17 (31.7-58.3)
LUNS4	No Unmet Need	53.89 (45.6-57.2)	52.50 (48.9-57.8)	55.00 (46.7-66.7)
	Unmet Need	54.44 (52.2-61.7)	52.78 (47.2-58.3)	41.67 (31.7-58.3)
LUNS5	No Unmet Need	46.67 (32.8-53.9)	49.44 (43.9-57.8)	61.67 (51.7-73.3)
	Unmet Need	57.22 (48.9-60.6)	52.78 (49.4-58.3)	48.33 (38.3-60.0)
LUNS6	No Unmet Need	48.89 (40.6-52.8)	52.22 (48.9-58.3)	55.00 (41.7-61.7)
	Unmet Need	57.22 (52.2-60.6)	52.78 (47.2-58.3)	48.33 (38.3-61.7)
LUNS7	No Unmet Need	43.33 (37.2-52.2)	50.00 (47.2-58.3)	55.00 (41.7-63.3)
	Unmet Need	57.22 (52.2-60.6)	52.78 (49.4-58.3)	50.00 (38.3-61.7)
LUNS8	No Unmet Need	53.89 (42.8-60.6)	52.22 (49.4-57.2)	51.67 (38.3-61.7)
	Unmet Need	53.89 (48.9-57.8)	53.33 (47.2-59.4)	50.00 (41.7-61.7)
LUNS9	No Unmet Need	52.22 (42.8-59.4)	52.22 (49.4-56.7)	53.33 (40.0-61.7)
	Unmet Need	54.44 (52.2-60.6)	53.33 (47.2-58.3)	50.00 (38.3-61.7)
LUNS10	No Unmet Need	48.89 (32.8-57.8)	49.44 (44.4-52.8)	55.00 (46.7-61.7)
	Unmet Need	54.44 (52.2-60.6)	53.89 (49.4-59.4)	50.00 (38.3-61.7)
LUNS11	No Unmet Need	53.89 (40.6-57.2)	50.00 (44.4-58.3)	55.00 (43.3-61.7)
	Unmet Need	53.89 (52.2-60.6)	52.78 (49.4-58.3)	50.00 (38.3-61.7)
LUNS12	No Unmet Need	55.56 (43.1-59.4)	51.39 (44.2-56.4)	56.67 (50.8-61.7)
	Unmet Need	53.89 (48.3-60.0)	52.78 (49.2-58.9)	49.17 (38.3-61.7)
LUNS13	No Unmet Need	52.78 (42.8-59.4)	52.22 (46.7-58.3)	55.00 (41.7-61.7)

	Unmet Need	57.22 (48.9-60.6)	52.78 (48.9-58.3)	48.33 (38.3-61.7)
LUNS14	No Unmet Need	47.78 (36.9-55.6)	49.72 (45.3-53.6)	56.67 (50.0-61.7)
	Unmet Need	55.83 (52.2-60.6)	53.06 (49.4-58.9)	48.33 (38.3-61.7)
LUNS15	No Unmet Need	52.78 (42.8-57.2)	51.94 (43.9-55.6)	55.00 (50.0-58.3)
	Unmet Need	54.44 (48.9-60.6)	52.78 (48.9-58.3)	48.33 (38.3-63.3)
LUNS16	No Unmet Need	47.78 (38.9-53.9)	50.00 (46.9-56.1)	56.67 (45.8-65.8)
	Unmet Need	57.22 (53.3-61.7)	54.17 (50.0-59.4)	47.50 (37.5-59.2)
LUNS17	No Unmet Need	53.89 (42.8-57.2)	52.22 (47.2-57.8)	56.67 (41.7-63.3)
	Unmet Need	53.89 (52.2-62.8)	52.78 (50.0-59.4)	46.67 (33.3-56.7)
LUNS18	No Unmet Need	53.89 (45.6-57.2)	51.11 (48.9-56.7)	51.67 (38.3-61.7)
	Unmet Need	57.22 (52.2-61.7)	53.33 (47.2-59.4)	50.00 (40.0-63.3)
LUNS19	No Unmet Need	53.89 (47.2-57.5)	52.50 (49.2-57.8)	51.67 (42.5-61.7)
	Unmet Need	53.89 (47.2-61.7)	52.78 (47.2-58.3)	47.50 (36.7-61.7)
LUNS20	No Unmet Need	43.89 (34.2-53.9)	48.89 (43.6-56.1)	61.67 (55.0-70.0)
	Unmet Need	57.22 (51.4-60.6)	52.78 (49.7-58.9)	46.67 (38.3-60.0)
LUNS21	No Unmet Need	43.06 (32.8-53.3)	49.44 (45.6-54.4)	59.17 (50.8-65.8)
	Unmet Need	57.22 (52.2-60.6)	52.78 (49.4-59.4)	47.50 (38.3-60.8)
LUNS22	No Unmet Need	53.33 (41.1-57.2)	51.94 (46.7-56.7)	55.83 (38.3-61.7)
	Unmet Need	54.44 (48.9-60.6)	52.78 (49.4-59.4)	50.00 (40.0-61.7)
Note: MCS = Mental Component Summary; PCS = Physical Component Summary; FAI = Frenchay Activities Index. IQR = Interquartile Range.				

Table 4.8: present the details of the validity analysis

LUNS Item	SF-12 MCS	SF-12 PCS	FAI
LUNS1	.06	-.04	-.16
LUNS2	.09	.09	-.10
LUNS3	.29**	.17	-.33**
LUNS4	.17	.06	-.32**
LUNS5	.38**	.12	-.31**

LUNS6	.37**	.05	-.09
LUNS7	.42**	.12	-.05
LUNS8	.04	.06	.03
LUNS9	.16	.07	-.05
LUNS10	.24*	.25*	-.15
LUNS11	.19	.11	-.12
LUNS12	.02	.11	-.09
LUNS13	.15	.00	-.06
LUNS14	.30**	.19	-.15
LUNS15	.12	.09	-.06
LUNS16	.49**	.25*	-.30**
LUNS17	.23*	.13	-.30**
LUNS18	.17	.13	.01
LUNS19	.07	-.02	-.16
LUNS20	.36**	.21	-.41**
LUNS21	.36**	.21	-.23*
LUNS22	.19	.10	-.09
Total LUNS Score	-.52**	-.22*	-.32**

Note: MCS = Mental Component Summary; PCS = Physical Component Summary;
FAI = Frenchay Activities Index.

* $p < .05$. ** $p < .01$.

4.4.3. Internal Consistency

The internal consistency of the Arabic LUNS was evaluated using Cronbach's alpha on the entire sample ($N = 80$). Cronbach's α for the 22-item LUNS questionnaire was 0.82, which indicates good internal consistency. This suggests that the items, although covering different domains, are sufficiently related in the context of measuring an overall construct of "unmet needs." In other words, stroke survivors who reported certain types of unmet needs were somewhat likely to report others as well, which is intuitive (for instance, someone with unmet therapy needs may also have unmet information needs or social needs).

It's worth noting that the LUNS is not necessarily intended to function as a unidimensional summative scale in a traditional sense (since it is often used as a checklist), but the alpha of 0.82 demonstrates that combining the items into a total score is psychometrically reasonable for summarizing overall need burden. No single item's removal would have markedly increased the alpha, indicating that each contributes some information.

Table 4.9 :shows the internal consistency reliability statistics. In our reporting, we focus on LUNS's alpha.

Scale	Cronbach's Alpha	Number of Items
SF-12	.79	12
Frenchay Activities Index (FAI)	.87	15
LUNS Questionnaire	.82	22

In summary, the results indicate that the Arabic version of the LUNS questionnaire is a reliable and valid instrument for capturing longer-term unmet needs in our sample of stroke survivors:

- It has stable test-retest reliability, both at the item level (with moderate to substantial agreement) and at the total score level (ICC well above 0.80).
- It shows meaningful correlations with established measures of health status (SF-12) and daily function (FAI), supporting its validity.
- It exhibits good internal consistency, implying that the items collectively measure a coherent construct.

These findings support the use of the Arabic LUNS in both clinical practice and research to identify unmet needs and possibly to evaluate interventions aimed at addressing those needs.

5. Discussion

This study set out to translate and validate the Longer-Term Unmet Needs after Stroke (LUNS) Questionnaire for Arabic-speaking stroke survivors, and the findings provide a number of important insights. In this chapter, we discuss the results in the context of existing literature, highlight the implications for clinical practice and research, and acknowledge the limitations of the study along with recommendations for future work.

5.1 Interpretation of Key Findings

Our results confirm that even many years post-stroke (in this sample, 5–8 years after the event), survivors continue to report a range of unmet needs. The high prevalence of unmet needs in areas such as information, medical follow-up, emotional support, and daily activities aligns with prior studies from other countries (Zawawi et al., 2020; Chen et al., 2019) which also found that information provision and psychosocial support are commonly lacking long-term. The specific finding that over 85% of participants desired more information about stroke underscores a critical gap in patient education in our context. This suggests that stroke survivors (and likely their families) are not receiving, or retaining, sufficient information about managing stroke aftermath and preventing secondary complications. Healthcare providers may need to implement more effective education strategies and repeated informational sessions even long after discharge.

The association between unmet needs and poorer outcomes (lower SF-12 and FAI scores) observed in our study is consistent with the notion that unmet needs can adversely affect quality of life and function. For example, participants who indicated unmet needs related to mobility or home adaptations tended to have lower FAI scores, meaning they were less active and engaged – likely because their needs for mobility aids or environmental modifications were not met. Similarly, those with many unmet needs had markedly lower mental health scores (SF-12 MCS). This supports the argument made by Andrew et al. (2016) that poorer quality of life is tied to long-term unmet needs. Our study reinforces that long-term stroke care should not only focus on physical recovery but also on holistic needs, including emotional well-being and social reintegration, since neglecting these can manifest in diminished mental health.

On a clinical level, the evidence that poorer health status and functional limitations are clearly related to the unmet needs identified by LUNS confirms the utility of the LUNS scale. In practical terms, if a patient is flagged by LUNS as having multiple unmet needs, clinicians can anticipate that this patient might be struggling in daily life and experiencing lower quality of life. Interventions can then be targeted accordingly. For example, a high LUNS score might prompt a referral to a social worker or a mental health specialist, in addition to conventional therapy, to address those extra needs.

The successful translation and cultural adaptation of LUNS into Arabic, demonstrated by the strong psychometric properties, is itself a major outcome. The Arabic LUNS retained good internal consistency ($\alpha = 0.82$, comparable to or even slightly higher than the original English version's α of ~ 0.74 reported by Rothwell et al. (2013)). This suggests that the items resonate similarly with Arabic-speaking survivors as they did with the original population, capturing a cohesive construct of unmet post-stroke needs. Furthermore, the test-retest reliability findings (kappa values mostly in moderate-to-substantial range) indicate that Arabic-speaking participants understood the questions consistently. The few items with only moderate agreement may reflect genuine changes in perceived needs over the two-week period or slight ambiguities that were interpreted differently upon re-test; however, none fell into the poor range, providing confidence in the instrument's stability.

The convergent validity of the Arabic LUNS is strongly supported by our data. The pattern of correlations, notably the moderate negative correlation with functional activity (FAI) and the even stronger negative correlation with mental health (SF-12 MCS), underscores that the LUNS is capturing aspects of the stroke survivor experience that are closely tied to real-world outcomes. This finding is in line with Forster et al. (2013), who also found that patients with unmet needs had worse outcomes on measures like SF-12 and FAI. It's worth highlighting that in our study, the mental component of QoL showed the highest correlation with unmet needs. This might indicate that emotional and social unmet needs are particularly impactful in our cohort; possibly even more so than physical unmet needs – or it could reflect that those with many unmet needs feel the burden more in terms of mental well-being.

5.2 Comparison with Previous Studies

Our work adds to the growing body of literature on LUNS and unmet needs by providing data from an Arabic population, which was previously missing. In other cultural validation studies of LUNS, similar steps were followed and similar challenges encountered:

- **Wellappuli et al. (2023)** adapted LUNS for a Sinhala-speaking population and found it necessary to use techniques like a modified Delphi to ensure content relevance. They reported that LUNS retained a multi-factor structure and had significant correlations with measures like GHQ-12 and the Barthel Index. Our findings of significant correlations with SF-12 and FAI parallel their evidence of convergent validity.
- **Groeneveld et al. (2018)**, working with a Dutch sample, found that 15 of 22 LUNS items were significantly associated with SF-12 or FAI components. We similarly found multiple items correlated with these outcomes, although direct item-to-item comparisons with Groeneveld's results are complicated by different sample characteristics (e.g., their sample was 5–8 years post-stroke like ours, which is interestingly similar, and they also found around 3–4 unmet needs median, whereas we found median 7 – possibly reflecting different healthcare contexts).
- The frequency of unmet needs in certain domains in our study can be contrasted with those reported in Western contexts. For example, **McKevitt et al. (2011)** in the UK noted common long-term needs like leisure activities, finance, and information. We also saw information and leisure/social as significant, but financial needs were less reported in our group. This could be due to cultural factors such as family support systems in Palestine that cushion financial strain, or differences in healthcare coverage.
- Our identification of informational needs as the top unmet need is consistent with findings from many countries (including developed ones) where patients often leave formal care without all the knowledge they desire. However, it might be exacerbated in our setting if access to stroke education resources (like support groups or educational materials in Arabic) is limited.

One novel aspect of our study is that it specifically addresses the Arabic language and cultural context. The Middle East and North Africa region has been under-represented in stroke

survivor needs research. Our findings suggest that, despite cultural and health system differences, Arabic-speaking stroke survivors share many of the same core challenges identified elsewhere (like the need for emotional support, therapy, and information). But at the same time, certain nuances may exist. For instance, we observed somewhat lower reporting of intimate relationship needs – it is possible that cultural norms made participants less forthcoming about that domain, or that family structures and caregiving in our society mitigate some issues (e.g., family members stepping in for personal care needs, thus survivors don't label them as “unmet” even if it's the family doing it rather than a service). This kind of nuance emphasizes why having a culturally adapted tool is important: survivors can respond within their cultural frame, and clinicians can interpret results with cultural context in mind.

5.3 Limitations

While this study contributes valuable information, it is not without limitations. First, our sample of 80 participants, although adequate for the analyses performed, was drawn by convenience from a specific region in Palestine. This may limit the generalizability of findings to all Arabic-speaking stroke survivors, who are spread across many countries with diverse dialects and healthcare systems. We attempted to minimize cultural bias through thorough translation and pilot testing; however, subtle differences in cultural norms, attitudes toward disability, and health-seeking behaviors across the Arab world might influence how some individuals interpret certain LUNS items. These differences could affect the reliability or validity of responses and limit the generalizability of our results beyond the Palestinian context. For example, an item about returning to work might be interpreted differently in a country with different social support or employment structures. Consequently, although our study makes a valuable contribution by establishing an Arabic version of LUNS, further research in other Arabic-speaking populations (e.g., in the Gulf countries, North Africa) would be beneficial to confirm its applicability and perhaps adjust for regional dialects or practices.

Second, there is a potential selection bias: participants who agreed to take part might be those more engaged with their rehabilitation centers or more concerned about their needs, whereas more isolated or dissatisfied survivors might not have participated (and they could have even higher unmet needs). Our inclusion criteria required participants to be attending

rehabilitation centers, which means we did not capture the needs of stroke survivors who are completely outside the healthcare follow-up system.

Third, our test-retest reliability was assessed in a subset of 20 participants. While the results were good, the small subset means the confidence intervals for some kappa values are broad. Also, we chose a ~2-week retest interval. This is standard for measuring reliability without expecting true change, but in that period some minor changes in a person's situation could occur (e.g., they might have received a new service or family help that addresses a need, or conversely a new need might arise). We did not strictly control for no interventions occurring between tests, so a little shift in perceived needs could reflect real changes rather than instrument unreliability.

Another limitation is related to the FAI and SF-12 measures we used for validation. The FAI relies on self-reported activity, which can be influenced by memory and mood. The SF-12, while validated, provides a broad quality of life measure that may not capture all specific consequences of unmet needs. Also, the SF-12 physical summary in stroke populations sometimes has limitations because it was originally designed for general populations. We proceeded with these as the best available standard measures; however, including a stroke-specific outcome like the Stroke Impact Scale could have enriched validity testing.

Finally, we must acknowledge that the LUNS questionnaire itself is a screening tool and does not prioritize needs or distinguish between met and unmet needs severity. In our analysis we treated all unmet needs equally. It's possible that some needs (for instance, needing help with walking) have a bigger impact on overall life than others (like needing home modifications for minor issues). We did not weight items, but future work might explore if certain unmet needs are more consequential than others.

5.4 Recommendations for Future Research and Practice

Building on our findings and acknowledging the limitations, we suggest several avenues for future work:

- **Broader Validation Studies:** Future studies should examine the applicability of the Arabic LUNS in other Arabic-speaking populations and regions. This could involve validating the questionnaire in countries across the Middle East and North Africa to ensure that dialectical differences or unique cultural contexts (for example, Bedouin communities, urban vs. rural differences) do not require further adaptation. Such studies can also increase the sample size and diversity, strengthening evidence for the tool's reliability and validity.
- **Qualitative Research:** We recommend qualitative investigations (e.g., in-depth interviews or focus groups with Arabic-speaking stroke survivors) to further explore how specific LUNS items are understood and to uncover any subtle cultural nuances in unmet needs. This approach could identify if any questionnaire items are consistently misunderstood or if important needs are not represented in the current list. It might also shed light on why certain needs (like intimate relationships or financial needs) were less frequently reported – whether truly less prevalent or simply less discussed.
- **Longitudinal Studies:** It would be valuable to conduct longitudinal research using the Arabic LUNS to track changes in unmet needs over time. Following stroke survivors beyond the 5–8 year window (or starting earlier and observing through that period) could reveal how unmet needs evolve or resolve, and what factors predict those changes. A longitudinal approach could provide important knowledge about the trajectory of unmet needs over time for Arabic-speaking stroke survivors, helping to identify critical periods for intervention. For instance, do unmet needs spike after formal rehabilitation ends? Do they gradually decline as survivors adjust, or do new needs emerge as they age?
- **Intervention Studies:** Now that a validated Arabic LUNS is available, it can be used as an outcome measure to evaluate interventions. Future studies could test whether specific programs (such as a post-stroke care coordination program or a patient education intervention) effectively reduce the number of unmet needs as measured by LUNS, and whether this leads to improved quality of life or other outcomes. The LUNS could also help stratify patients in trials – for example, targeting those with high unmet needs for certain interventions.
- **Integration into Clinical Practice:** On a practical note, rehabilitation professionals and healthcare providers in Arab countries should consider integrating the LUNS (Arabic

version) into routine follow-up assessments for stroke survivors. Doing so can systematically identify issues that might otherwise be missed in standard medical follow-ups. Collaboration with healthcare providers and community services is essential to facilitate the effective use of the Arabic LUNS in practice and to ensure that it guides the provision of comprehensive post-stroke support. For example, if a rehabilitation clinic adopts the LUNS as part of discharge or outpatient visits, they should also have a referral network in place (psychologists, social workers, support groups, etc.) to address the needs that are uncovered.

- **Policy and Education:** The high informational needs point to a policy-level recommendation: stroke education materials (pamphlets, websites, community seminars) should be developed or improved in Arabic. Policymakers and healthcare organizations should be made aware (through dissemination of studies like ours) that long-term stroke survivors require ongoing support. The results of this study should be disseminated to stakeholders – including health ministry officials, rehabilitation program directors, and patient advocacy groups – to highlight the importance of long-term follow-up and resource allocation for stroke aftercare.

In conclusion, our study provides a foundation for addressing longer-term unmet needs among Arabic-speaking stroke survivors. It emphasizes that beyond the acute and subacute phases of stroke care, there is a continuing journey of recovery and adjustment in which many patients feel underserved. By empowering patients and clinicians with a culturally attuned tool like the Arabic LUNS, we can better identify these gaps and work towards bridging them, ultimately aiming to improve the quality of life of stroke survivors in the Arab world.

5.5 Conclusion

By developing and validating an Arabic version of the LUNS questionnaire, this study has filled a critical gap in stroke care for Arabic-speaking communities. The Arabic LUNS has proven to be a reliable and valid instrument for uncovering the array of longer-term unmet needs experienced by stroke survivors. Our findings underscore the significance of these needs: survivors reporting more unmet needs also tend to have worse functional outcomes and lower quality of life. This highlights the practical value of having a translated scale – it enables

healthcare providers to systematically assess areas that require intervention, many of which might otherwise go undiscussed during routine clinic visits.

The implications of this work are far-reaching. Clinicians can use the Arabic LUNS to conduct comprehensive needs assessments during follow-up appointments, thereby identifying issues that extend beyond the traditional medical model (such as emotional or social needs) and ensuring that referrals or resources are provided. For instance, if a patient's LUNS responses indicate a need for more information and emotional support, educational sessions and counseling can be arranged. If many patients exhibit a particular unmet need, healthcare administrators can notice patterns and allocate resources accordingly (for example, starting a community stroke club or a caregiver training program).

Furthermore, the study's results should motivate dissemination to relevant stakeholders. Rehabilitation centers, stroke clinics, and community health programs in Arabic-speaking regions should be informed about the availability of the Arabic LUNS and trained in its use. Policymakers and healthcare planners can also use the insights from LUNS data to advocate for and design services that address prevalent unmet needs – such as integrating long-term follow-up programs, home-based rehabilitation services, or informational hotlines for stroke survivors.

Ultimately, the significance of our findings lies in affirming that stroke recovery is not complete at hospital discharge or even after initial rehab; stroke survivors continue to face multiple challenges years down the line. The Arabic LUNS questionnaire is now an evidence-based tool that can facilitate the identification and prioritization of these challenges in a culturally appropriate manner. By doing so, it can guide interventions and policies aimed at improving survivors' quality of life. For example, high unmet needs in our cohort related to information and medical follow-up point to a need for establishing stroke survivor education workshops and more structured follow-up clinics. Unmet emotional needs point to the importance of psychosocial support services, such as stroke support groups or mental health integration in stroke care.

In conclusion, this study not only offers a validated Arabic instrument but also reveals critical areas of need for stroke survivors in Arab communities. Addressing these unmet needs

through targeted interventions could significantly enhance the long-term well-being and reintegration of stroke survivors. Going forward, it is crucial that healthcare providers, researchers, and policymakers utilize the knowledge gained from the Arabic LUNS to implement changes in the continuum of stroke care – ensuring that stroke survivors are not left to cope in isolation with needs that we now can clearly identify and should strive to meet.

5.6 Limitations and Recommendations

Limitations: As discussed, this study’s sample was region-specific and relatively small, which may affect generalizability. The cultural adaptation was comprehensive, but it is possible that certain dialectical nuances in other Arabic-speaking regions could require minor adjustments to the questionnaire. Additionally, while the LUNS captures whether a need is unmet, it doesn’t quantify the severity of that need or the adequacy of resources available, which could be explored in future research.

Recommendations: Future research should validate the Arabic LUNS in other countries and contexts, and use qualitative methods to ensure all items are interpreted as intended across different Arabic cultures. Longitudinal studies are recommended to monitor how unmet needs change over time and to evaluate the impact of specific interventions (such as educational programs or follow-up services) on reducing unmet needs. From a clinical perspective, it is recommended that stroke rehabilitation programs adopt the Arabic LUNS as part of routine follow-up assessments. Training healthcare professionals in its use will be important, along with establishing referral pathways to address identified needs (for example, developing a network of psychologists, social workers, physiotherapists, and patient support groups that patients can be referred to depending on their LUNS results).

Collaboration between healthcare providers and community organizations is also recommended to effectively implement the LUNS findings. By working together, they can ensure that identified needs (whether medical, emotional, or social) are met through coordinated care plans, thus bridging the gap between hospital discharge and community living for stroke survivors.

In summary, the Arabic version of the LUNS questionnaire is now available as a useful tool for improving stroke survivor care. By highlighting and addressing the longer-term unmet needs identified through this tool, stakeholders can make meaningful improvements in survivors' rehabilitation experiences, ultimately striving toward a more holistic and sustained recovery process.

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Appendices

Appendix 1 :IRB approval

Arab American University- Palestine
Deanship of Scientific Research
IRB committee
Tel: 04-241-8888, ext 1196
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الجامعة العربية الأمريكية
مجلس البحث العلمي
لجنة المخططات البحث العلمي
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IRB Approval Letter

Study Title: The Longer-term Unmet Needs after Stroke Questionnaire: Cross-Cultural Adaptation, Reliability and Validity of the Arabic Population.

Submitted by: Mahmood Yaqoob Alshkarna

Date received: 17th June 2023

Date reviewed: 5th September 2023

Date approved: 5th September 2023

Your Study titled "The Longer-term Unmet Needs after Stroke Questionnaire: Cross-Cultural Adaptation, Reliability and Validity of the Arabic Population," with archived number 2023/A/133/W was reviewed by the Arab American University IRB committee and was approved on the 5th September 2023.

<p>Ahmed Ayed, PhD IRB Committee Member Arab American University of Palestine</p> 	<p>Sajed Ghawadra, PhD IRB Committee Vice-chairman Arab American University of Palestine</p> 	<p>Reham Khalaf-Nazzari, MD, PhD IRB Committee Chairman Arab American University of Palestine</p> 
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General Conditions:

1. Valid for 6 months from the date of approval.
2. It is important to inform the committee with any modification of the approved study protocol.
3. The committee appreciates a copy of the research when accomplished.



لجنة المخططات البحث العلمي في الجامعة العربية الأمريكية
IRB of Arab American University

Appendix 2: Questionnaire

LUNS version 1 2008

Page 1 of 2

Longer-term Unmet Needs after Stroke LUNS

Please read each statement and answer it as follows

Tick 'YES' if you agree with the statement

Tick 'NO' if you do not agree with the statement or it doesn't apply to you

	YES	NO
1. I would like more information about my stroke (e.g. what is a stroke, why it has happened to me and how to avoid having another one)	<input type="checkbox"/>	<input type="checkbox"/>
2. I haven't had my medication/blood pressure checked for some time and would like a check up	<input type="checkbox"/>	<input type="checkbox"/>
3. I regularly get pain and nothing seems to ease it	<input type="checkbox"/>	<input type="checkbox"/>
4. My walking and general moving seems to be getting worse and I'm not getting any help with this	<input type="checkbox"/>	<input type="checkbox"/>
5. I am worried that I might fall (again) and this is stopping me from doing my usual things	<input type="checkbox"/>	<input type="checkbox"/>
6. I need additional aids (e.g. kitchen equipment) or adaptations (e.g. stair lift, grab rails) inside the home	<input type="checkbox"/>	<input type="checkbox"/>
7. I need adaptations outside the home (e.g. ramp, rail) but they haven't been ordered yet or I've been waiting too long	<input type="checkbox"/>	<input type="checkbox"/>
8. I need some help / advice about getting back to driving and / or getting a blue badge	<input type="checkbox"/>	<input type="checkbox"/>
9. I would like to find out about travelling on buses, taxis and / or trains	<input type="checkbox"/>	<input type="checkbox"/>
10. I would like outside help to get jobs done in my home (e.g. cleaning, cooking, ironing, fixing things)	<input type="checkbox"/>	<input type="checkbox"/>

Please Turn Over

	YES	NO
11. I would like to look into the options for moving to another home	<input type="checkbox"/>	<input type="checkbox"/>
12. I would like some advice about how to improve my diet (e.g. alcohol, sugar, fat and salt intakes)	<input type="checkbox"/>	<input type="checkbox"/>
13. I need some advice to help me manage my money better (e.g. paying bills, getting my pension)	<input type="checkbox"/>	<input type="checkbox"/>
14. I would like help to find out about, or to apply for benefits	<input type="checkbox"/>	<input type="checkbox"/>
15. I would like advice on employment after stroke	<input type="checkbox"/>	<input type="checkbox"/>
16. I need more help with things like cutting my toenails, washing myself or dental care (including dentures)	<input type="checkbox"/>	<input type="checkbox"/>
17. I have problems with my bladder / bowel (accidents, constipation, diarrhoea) and would like some help with this	<input type="checkbox"/>	<input type="checkbox"/>
18. I am concerned about my physical relationship with my partner and would like some advice or information	<input type="checkbox"/>	<input type="checkbox"/>
19. I forget things quite a lot or find it hard to concentrate and would like some help with this	<input type="checkbox"/>	<input type="checkbox"/>
20. I often feel quite low, angry or worried and would like to find out what help is available	<input type="checkbox"/>	<input type="checkbox"/>
21. I would like to occupy my day better (e.g. social outings, home library, hobbies) but don't know how to go about it	<input type="checkbox"/>	<input type="checkbox"/>
22. I would like to find out about holidays / breaks (including transport) that cater for people with disabilities	<input type="checkbox"/>	<input type="checkbox"/>

استبيان الاحتياجات غير الملباة على المدى الطويل بعد السكتة الدماغية: التكيف عبر

الثقافات، والموثوقية، والصلاحية لدى السكان العرب

محمود يحيى محمد أبو خرمة

د. دعاء الواوي

د. هشام عرب الكعبية

د. سمية برهان أبو جابر

الملخص باللغة العربية

الخلفية: تشكّل الاحتياجات غير الملباة لدى الناجين من السكتة الدماغية محورًا أساسيًا في مسار التأهيل طويل الأمد، إذ تمتد هذه الاحتياجات لتشمل الجوانب الجسدية والنفسية والاجتماعية، مما ينعكس سلبيًا على جودة الحياة. ويُعد توفر أدوات تقييم مُحكمة ومتكيفة ثقافيًا أمرًا ضروريًا لفهم هذه الاحتياجات ومعالجتها بصورة منهجية. ومع غياب أداة عربية شاملة لتقييم الاحتياجات غير الملباة بعد السكتة الدماغية، تبرز الحاجة إلى تطوير نسخة عربية صالحة وموثوقة من استبيان LUNS.

الهدف: هدفت هذه الدراسة إلى ترجمة استبيان الاحتياجات غير الملباة على المدى الطويل بعد السكتة الدماغية (LUNS) إلى اللغة العربية، وتكيفه ثقافيًا، والتحقق من خصائصه السيكومترية لدى الناطقين بالعربية ممن تعرضوا لسكتة دماغية.

المنهجية: أُجريت دراسة مقطعية متعددة المراكز في أربعة مراكز تأهيلية في مدينتي رام الله والبييرة بفلسطين، وشملت عينةً مكوّنةً من (80) مشاركًا ممن تراوحت فترة ما بعد إصابتهم بالسكتة بين 5 و8 سنوات، وفق أسلوب العينة المتاحة. تمت عملية الترجمة والتكيف الثقافي وفق معايير معتمدة دوليًا لضمان المكافأة

اللغوية والدلالية والمفاهيمية. كما جرى فحص الخصائص السيكومترية للاستبيان، بما في ذلك الثبات بإعادة الاختبار والصدق المتزامن، من خلال مقارنته باستبيان SF-12 للصحة العامة ومؤشر أنشطة فرينشاي .FAI.

النتائج: كشف تحليل الثبات بإعادة الاختبار عن مستوى اتفاق تراوح بين المتوسط والمرتفع وفق معامل كابا لكوهين (0.45-0.67)، بينما أظهر الاتساق الداخلي موثوقية مرتفعة (ألفا كرونباخ: 0.771-0.874). كما دلّت نتائج الصدق المتزامن على وجود ارتباطات ذات دلالة إحصائية بين بنود الاستبيان والمقاييس الصحية المقارنة، بما يتوافق مع التوقعات النظرية. وكانت أكثر الاحتياجات غير الملباة تكراراً لدى المشاركين هي الحاجة للحصول على معلومات حول السكتة الدماغية (86.3%) والحاجة إلى المتابعة الطبية والفحوصات الدورية (62.5%).

الخلاصة: تُعد النسخة العربية من استبيان (LUNS) أداة موثوقة وصالحة لقياس الاحتياجات غير الملباة لدى الناجين من السكتة الدماغية في السياق العربي، مما يسهم في سد فجوة بحثية في ميدان تأهيل ما بعد السكتة. كما توفر هذه الأداة أساساً علمياً لدعم تصميم تدخلات فردية أكثر دقة، تمهيداً لتحسين جودة الحياة وتعزيز نتائج التأهيل طويلة المدى

الكلمات المفاحية: الاحتياجات غير الملباة على المدى الطويل بعد السكتة الدماغية، السكتة الدماغية، الترجمة العربية، التحقق النفسي، الاحتياجات غير الملباة.