

**Assessing the Quality of Life among Saudi Patients  
with Aphasia after Stroke**



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# Abstract

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Although there is a growing literature on the impact of aphasia on quality of life (QoL), this has focused on western Christian rather than Arabic cultures. While a few QoL studies have been conducted in Arabic countries, employing translated, culturally unadapted assessment tools, none have considered people with aphasia (PWA). Given the cultural and religious context, this gap needs to be redressed and so this study explored the factors affecting QoL for Saudi PWA, developed a tool to assess QoL, and explored other predictors affecting it.

A three-stage qualitative and quantitative approach was used. First, a QoL questionnaire was developed by reviewing existing measures of QoL for aphasia in the light of cross-cultural adaptation, and surveying opinions on QoL and aphasia. Thematic analysis was then employed to produce a questionnaire, which was piloted and then revised. Second, another pilot test was implemented and its properties were examined by factor analysis, producing a shorter version. Third, this version was also piloted and its psychometric properties, accessibility and acceptability were examined. Potential predictors of QoL for demographic and health-related factors for Saudi PWA were then measured.

After the review, three main measures were used to develop the questions. Thematic analysis resulted in a developed scale containing 58 items, covering areas such as physical and daily life activities, and communication. This scale was valid and reliable ( $r = 0.992$ ;  $\alpha = 0.896$ ). For the potential predictors, it was found that QoL became worse as factors such as age and severity of aphasia increased. However, gender, post-onset time and employment variables seemed to have no significant effect.

The QoL of Saudi PWA centred on mobility, communication, and social participation. Contrary to predictions, religion did not affect QoL despite its importance in Saudi culture, so further research could be conducted on the questionnaire's psychometric properties, and its clinical implications.

# Dedication

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This thesis is dedicated with appreciation to:

The memory of my father (God bless his soul) who originally inspired my love for knowledge and sciences throughout my life and established the fundamental nature of my learning character, showing me the joy of intellectual pursuit, ever since I was child.

The greatest person in my life, my mother, who raised me and my children as well, who taught me the meaning of endless giving; my life would be meaningless without her blessings and prayers. May Allah reward her with paradise.

My beloved wife and my children, who have all stood by me, and dealt with my absences with a smile to the end of this journey.

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# Chapter 1 Literature Review

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## 1.1 Background

Aphasia is an acquired neurogenic communication disorder that mainly affects expressive and receptive language abilities; it has an impact on an individual's life in general, in terms of their role, position and participation in society, and it also has psychological effects. These effects also include the people around them. As some authors have noted, for example Cruice, Worrall, Hickson, and Murison (2005), and Ross and Wertz (2003), although aphasia is considered a language-based communication disorder, other aspects of an individual's life may be affected as well as a result of this disorder. Ross and Wertz (2003) reported that patients with aphasia (PWA) had significantly lower scores on standardized Quality of life (QoL) assessments compared to people without aphasia.

The literature also demonstrates that subjective effects on the patient may not be recognizable by an observer (Cruice et al., 2005; Engell, Hütter, Willmes, & Huber, 2003; Hilari, Owen, & Farrelly, 2007), and therefore it is necessary to assess QoL from the point of view of the PWA to explore areas that are negatively affected by aphasia. This need is supported by the American Speech-Language-Hearing Association's (ASHA) practice guidelines for Speech Language Pathologists (SLPs). According to these guidelines, entitled SLPs should work "to optimize individuals' ability to communicate and swallow, thereby improving quality of life" (American Speech-Language-Hearing Association, 2007, p.3). Therefore, for SLPs, an assessment of QoL may be substituted when the primary goal of aphasia rehabilitation programmes is not achieved, to improve QoL (Simmons-Mackie & Kagan, 2007).

Worrall and Holland (2003) discussed how QoL measures have major implications for the development and evaluation of policies in the health care field, the distribution of resources, future health care plans and programmes, the implementation of health-related surveys, and the evaluation of the efficacy of clinical treatments and research trials. Also, assessing QoL for PWA can provide a broader insight into their values, perspectives and personal well-being, by understanding the patient's own perspective on QoL. This is important in selecting appropriate and effective interventions during the rehabilitation

process. Furthermore, measuring QoL is considered to be a crucial outcome measure which can be used by clinicians as a tool for the purposes of accountability in effective interventions.

Experiences of aphasia as a result of stroke, and the subsequent recovery process which affects the person's life, are issues that may be influenced by cultural and religious beliefs, values and norms; however, there is limited available evidence on the impact of these features on QoL. The review of the literature has revealed that the majority of published research on QoL, life satisfaction, subject well-being, and religion has been carried out in western societies and cultures. There is, then, a significant gap in our knowledge of QoL among PWA from Arabic cultures, with the associated Islamic beliefs and social values.

## **1.2 Introduction**

This chapter will first consider definitions of quality of life (QoL) and how this relates to health-related quality of life (HRQoL) and the purpose of QoL and HRQoL measures. Then, it will demonstrate the relationship between aphasia and stroke and how this relates to QoL. This will be followed by exploring how QoL is assessed in PWA and discussing the dilemma of using proxies in the assessment of QoL for these patients with communication difficulties. Then, the chapter will provide an overview of studies found in the literature about QoL in the Arabic culture and context both in general and specific to aphasia, in addition to the procedures employed for these measures, such as direct translation and the cross-cultural adaptation process. After this, it will demonstrate the presence of stroke and aphasia in Saudi Arabia and its relation to QoL, and then demonstrate the importance of religion and culture and reflect on these in relation to QoL for PWA. Finally, it will present the hypothesis generated by this literature and the research questions addressed by this study.

## **1.3 The concept of quality of life (QoL)**

A commonly accepted definition of QoL is presented by the World Health Organization (WHO) as “individual's perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad-ranging concept, incorporating in a complex way the person's physical health, psychological state, level of independence, social relationships, and their relationship to salient features of their environment” (WHOQoL Group, 1994, p. 43). This definition views QoL as a subjective assessment that is based on the individual's

cultural, social and environmental circumstances, and it is this definition which will be used for this study.

However, QoL as a concept arises from different fields and backgrounds and so can be viewed from different perspectives. As a multi-contextual concept, QoL research is multi-disciplinary due to these different backgrounds (Abdel-Khalek, 2010a; Fernandez-Ballesteros, 1998). Moreover, there are both objective and subjective indicators for QoL. Objective indicators may involve access to leisure facilities, and take into account the type of housing and assets the individual has, in addition to personal wealth, monthly income, level of safety and medical statistics. Subjective indicators involve a subjective evaluation of a person's life, which is essentially based on personal reports about their life circumstances.

Concepts of QoL have been used synonymously, with the most common terms for QoL being 'subject well-being' and 'life satisfaction'. Campbell (1981) defined QoL as being equal to subject well-being, but the term has also been used to mean life satisfaction in some literature; Sousa and Lyubomirsky (2001) used the term life satisfaction for QoL and defined it as "a contentment with, or acceptance of, one's life circumstances or the fulfilment of one's wants and needs for one's life as a whole" (p.667). Omu, De souza, and Reynolds (2010) stated that "the use of the term 'quality of life' was found to be more widely used than life satisfaction in health research" (p.50).

QoL is thus variously defined by different authors, who have seen it as an "abstract", "soft" and "amorphous" concept (Birren & Dieckmann, 1991, pp. 344-345), or one which "has no fixed boundaries" (Hughes, 1990, p. 47). Furthermore, Andersen, Davidson, and Ganz (1994) stated that "it has been exceedingly difficult to define QoL precisely" (p.367), while Fowlie and Berkeley (1987) explained its definition as that "the meaning is dependent on the user of the term" (p.226). Adding more detail, Tate and Forchheimer (2002), stated that "the subjective definitions of QoL include the following concepts: well-being, life satisfaction, morale, and happiness" (p.401).

There is no single agreed definition for QoL, partly due to its complex and abstract nature, but also because it is used in different disciplines such as the social, medical, and psychological sciences, and even in the field of public policy. For example, in the field of health and social sciences it has been defined as satisfaction with areas of life that are held important to a person (Ferrans & Powers, 1992; King, 1996), with the concept of

QoL being seen as an ambiguous and multi-dimensional structure that theoretically integrates all aspects of a person's life (Bowling, 1995). It can, therefore, be said that the different definitions of QoL are based on the views of the authors or users themselves, arising from the fields or disciplines in which this term is used.

From the literature, it can be said that most of the definitions of QoL indicate that it is a subjective and individualistic concept that refers to a personal interpretation of life. Thus, the concept of QoL is subject to numerous interpretations, but it clearly defines a prominent goal in a wide range of endeavours, such as patient care, health care systems and social programmes. Also, it has been conceptualized in different ways to reflect the particular knowledge, experience and values of each individual.

#### **1.4 The concept of health-related quality of life (HRQoL)**

In the field of health research and practice, the term QoL usually refers to a multi-dimensional construct relating to symptoms, impairment, functional and emotional states, and health domains (McDowell, Newell, & McDowell, 2006). This use of QoL is clearly disconnected from the general use of the term, and so researchers in the health field have taken to referring to the QoL construct as HRQoL. The QoL concept has been converted into HRQoL in the field of health, since the WHO expanded the concept of health to include physical, mental and social well-being, rather than simply the absence of disease. HRQoL is the most commonly used category at the individual level in the QoL studies reviewed, and has been used as an overlapping term with QoL in almost two thirds of studies (Halvorsrud & Kalfoss, 2007). Carr, Gibson, and Robinson (2001) defined QoL as “the impact of a person's health on his/her ability to lead a fulfilling life” (p.1240). This definition directly relates health with QoL and appears to suggest that it is somehow a measure of the ability to live a fulfilling life, but also that it is health dependent, thus leading to the more appropriate term in the literature of HRQoL. This definition has been described by Sturm, Donnan, Dewey, Macdonell, Gilligan, Srikanth, and Thrift (2004) as “those specific aspects of quality of life that are affected by disease process” (p.2340). Arising from all these definitions of health from different philosophical approaches and different perspectives, although there is no exact definition of health, it is generally accepted that health is related to wellbeing and includes physical, mental and social components (Berzon, Hays, & Shumaker, 1993).

For the purpose of health evaluation, HRQoL has been seen as a reflection of the impact of the state of a person's health on that person's ability to lead a fulfilling life (Bullinger, Anderson, Cella, & Aaronson, 1993). Also, this definition combines areas identified by the long term disabled as being most affected by their illness, including physical/functional and social aspects of life (Bowling, 1995). On the other hand, O'Boyle, McGee, Hickey, O'Malley, and Joyce (1992) define HRQoL as what the patient says it is or what is described by the patient themselves; this definition was quoted by Bech (1993) in a discussion of the subjective nature of HRQoL and how it can be assessed through physical, cognitive, affective, social, economic and ego functions. In this way, it can be said that QoL and HRQoL are often used interchangeably in health research.

### **1.5 Purposes of QoL and HRQoL measures**

The definition of health by the WHO implies that when a person is ill or has a disease almost all aspects of life become health-related (Guyatt, Feeny, & Patrick, 1993). This definition reflects the shift which has occurred regarding the concept of HRQoL from being just a simple concept of disease or its absence to the social impact of this disorder or disease. Indeed, according to Berzon et al. (1993), an international group of HRQoL researchers from the International Society for Quality of Life Research reached an agreement to include within a HRQoL measure physical, mental/psychological, and social health, as well as the global perception of function and well-being. It can therefore be said that measuring the QoL of an individual means assessing these different areas, and not just the individual's health status.

Assessing QoL is connected to its definition and the areas it covers. The WHO definition of QoL (1994) provides four main domains of overall QoL, which are physical health, psychological status, social relationships, and environment, all of which reflect a subjective view of QoL that is rooted in the person's cultural, social and environmental background. As a result, to assess QoL the measure should include these four domains. The spirituality/ religion/ personal beliefs domain was added later in the newly developed form of the assessment for QoL as WHOQoL-100, which was developed by the WHOQoL group to be cross-culturally applicable (WHOQoL Group, 1997). According to the WHO Group (1998), the ideal assessment of health would include a measure of a person's physical, social and psychological functioning, and a measure of QoL.

There are different goals for QoL measures, and authors such as Arnold (1991), and Fernandez-Ballesteros and Santacreu (2013), have pointed out that there are five purposes for measuring QoL, which are as follows: 1) to have a better understanding of the causes and effects of differences in QoL between people or specific groups of people; 2) evaluating how QoL can be affected by the social and environmental conditions; 3) determining the estimated needs of a given population; 4) evaluating the efficiency or effectiveness of the health interventions and quality of health care services provided; and 5) improving the decision making process in clinical settings.

HRQoL measures are particularly useful in the evaluation of health care interventions for people with chronic diseases and disabilities (Hilari, Wiggins, Roy, Byng, & Smith, 2003). According to Patrick and Erickson (1993), patient-based HRQoL measures are suitable in the health care field for the evaluation of people with chronic disabilities, as they allow for a better understanding and measurement of the impact of disease on the patient's life as a whole. Furthermore, they are needed to determine the effectiveness of the treatment, in order to improve health care services for patients (Buck, Jacoby, Massey, & Ford, 2000).

This kind of measure is applied to aphasia as a result of stroke as one of the chronic diseases and disabilities that has an impact on PWA. To understand these effects in relation to QoL, it is necessary to understand the nature of aphasia and stroke in relation to each other and in relation to QoL as well.

### **1.6 Technical aspects of developing QoL measures:**

The review of the literature on measuring QoL identified different techniques used when developing QoL measures. The literature suggests that QoL is a multi-factorial concept that investigates a substantial number of domains or factors. A major aspect of a scale/measure is the determination of a number of items that should comprise a particular scale, and how consistently these items hold together. Therefore, the testing of the adequacy and validity of the models for QoL scale/measure is based upon a suggested construct, and an estimation of the values of the latent variables/factors that comprise these models. Under the latent variable model, it is assumed that the data structure that can be divided up into a number of hypothetical constructs.

The literature review has shown that factor analysis is a common technique used in developing QoL measures. A factor analysis (FA) approach can be used to model a

number of factors, using the inter-item correlations and standard deviation to estimate the models. The factor structure models are a combination of observed variables, with latent variables being estimated by weighted summation that reflects the importance of each of these variables. FA is one an important and powerful method for establishing the construct validity of psychometric tests, and attempts to provide a formal method of exploring correlation structure, as well as investigating the internal structure of the measure and the reliability of the assessment (Fayers & Machin, 2007).

FA can be used either as a procedure to explore the patterns amongst the correlations (exploratory factor analysis, or EFA), or as a confirmatory method (CFA) for testing whether the correlational pattern corresponds to the expected structure of the scale/measure. Thus, FA plays a major role in construct validity. EFA is the form most commonly seen in QoL research, as it is simpler to implement than CFA and does not need specific details of the scale structure and the inter-item relationships in advance. In contrast, CFA tests whether the pre-specified model is adequate to fit the observed data. Both types of FA are concerned with investigating and analysing patterns in the inter-item correlation matrix and can be used to assess the number of factors needed to represent the variability in the data and identify those groups of variables/items that constitute one factor. EFA does not make use of any prior knowledge about the structure or proposed structure of the measure/scale/questionnaire and offers facilities for assessing the number of factors necessary to explain the data.

In regard to the interpretation, most FA programs use eigenvalues to determine how many factors are present and a commonly used criterion is the greater than one criterion. After deciding the number of factors in the model, the next step is to obtain the factor pattern matrix (factor loadings) corresponding to the factor solution, where these numbers indicate the importance of variables to each factor. The loadings are also equal to the correlation between the factors and items involved, so the items that should be included in a particular factor or construct are identified. This is followed by factor decomposition of the data set, where the procedure of rotation is used to find as many as possible of the items that contribute to single factors. This rotation can be as simple as orthogonal, and varimax is commonly used to produce sensible solutions. The literature shows that, in spite of problems and difficulties in applying FA, it seems that FA of QoL measures often results in sensible factors and reflects the strength of the correlation structure that underlines many constructs of the measure/scale (Fayers & Machin, 2007).

## 1.7 Aphasia and stroke

To measure QoL for PWA, Kagan, Simmons-Mackie, Rowland, Huijbregts, Shumway, McEwen, Threats, and Sharp (2008) argue that professionals can use these measures as an essential tool for setting objectives on improving aspects of an individual's QoL based on the person's perspective. Therefore, an understanding of the impact of the disorder and how it affects a person's life is required when measuring QoL.

Understanding the nature of the aphasia, its impacts and its causes will help in exploring the most affected areas and establishing how to improve them. Aphasia refers to language impairments that can affect many aspects of communication, including speech, writing, reading, gestures and the comprehension of spoken and written language, and it varies in degree from mild to severe (Code & Herrmann, 2003). Also, aphasia is described as "a disorder of communication leading to a disorder of the person" (Sarno, 1993, p. 323). It can be caused by a stroke or by any injury to the brain such as head injury and brain tumour. In western countries, stroke is considered the most common cause of long-term adult disability (Hilari, 2002) and it is the most common cause of aphasia (Enderby et al., 2009). Various studies have estimated that anywhere between 20-38% of acute stroke patients will experience aphasia (Dickey et al., 2010). However, these studies vary considerably in terms of their design, diagnostic criteria for aphasia, and sample size. On the basis of stroke data, the incidence of aphasia in the developed world ranges between 0.02-0.06%, with prevalence ranging between 0.1-0.4 % (Code & Petheram, 2011).

It is important to have knowledge about the incidence and prevalence of the stroke and aphasia in order to have a general picture about how aphasia post-stroke affects many peoples' lives. Therefore, for epidemiological purposes, the occurrence of cases of disease must be related to the "population at risk" giving rise to the cases. There are several measures of disease frequency which are in common use and found in most epidemiological and public health studies, and also used in most of the research on aphasia and stroke. A distinction needs to be drawn between them as they will be used frequently here. The first measure concerns *incidence*: the incidence of a disease is the rate at which new cases occur in a population during a specified period. When the population at risk is roughly constant, incidence is measured as: number of new cases: population at risk  $\times$  time during which cases were determined. The other measure is *prevalence*: the prevalence of a disease is the proportion of a population that are cases at a point in time. Prevalence is an appropriate measure only in relatively stable conditions,

and it is unsuitable for acute disorders. Another measure is *crude and specific rates*: crude incidence, prevalence, or mortality (death rate) is one that relates to results for a population taken as a whole, without subdivision or refinement (Oakes & Kaufman, 2006).

In the United Kingdom (UK), there are no official figures on the incidence and prevalence of aphasia post-stroke (Taylor-Goh, 2005). However, the estimates of incidence and prevalence of aphasia post-stroke vary (Mackenzie, 1992), which is also cited in Greener, Enderby, and Whurr (2008). The incidence of stroke in the UK is approximately 150,000 people every year with 1,000 of them under the age of 30 years and with a prevalence of 47 per thousand population, aged 55 years and over and 15 per thousand population –all ages (The Stroke Association, 2008, cited in Enderby et al., 2009).

According to Greener et al. (2008), the incidence of aphasia in the UK is estimated at 11,400 people every year following stroke, and it has also been noted that aphasia was present in a quarter of conscious patients who had suffered a stroke within the previous seven days, with 12% of the stroke survivors still being aphasic six months after the incident. The prevalence of aphasia for the same period has been estimated to be 50 per 100,000/ population after stroke. Enderby and Emerson (1996) estimated the UK incidence of aphasia 66 per 100,000 population. Also, one third of stroke survivors were affected by aphasia (Bakheit et al., 2007; Van der Gaag et al., 2005). Therefore, from these figures it can be imagined how aphasia due to stroke affects such a large number of peoples' lives.

## **1.8 Stroke and QoL**

The potential impact and consequences of stroke can vary, and so studying these effects is crucial to gain a better understanding of QoL for PWA post-stroke. In the literature, many stroke studies have indicated that QoL in patients with stroke has been influenced by depression, and the physical and social functioning disabilities that they experience are the most common determinants of QoL after stroke (e.g., Bays, 2001; Jaracz, Jaracz, Kozubski, & Rybakowski, 2002; Kim, Warren, Madill, & Hadley, 1999). While depression is cited by a number of studies as the factor which most greatly affects QoL (e.g. Jonkman, Weerd, & Vrijens, 1998; Kauhanen et al., 2000; Naess, Waje-Andreassen, Thomassen, Nyland, & Myhr, 2006), other studies have found that aspects of social support are worst affected by stroke (e.g. Aström, Asplund, & Aström, 1992; Bays, 2001; King, 1996; Wyller, Holmen, Laake, & Laake, 1998). The majority of these latter studies

have found that reduced QoL is associated with reduced physical and daily life activities (e.g. Ahlsjö, Britton, Murray, & Theorell, 1984; Carod-Artal, Egido, González, & De Seijas, 2000; Niemi, Laaksonen, Kotila, & Waltimo, 1988).

There are other factors/predictors that have been associated with QoL after stroke. Age is one of these predictors, but it is not a straightforward relationship. For example, although age affects QoL in general, some authors have found that reduced QoL after stroke is associated with older age population (Aström et al., 1992; De Haan, Limburg, Van der Meulen, Jacobs, & Aaronson, 1995; Niemi et al., 1988), while in other studies no age effect has been found (Ahlsjö et al., 1984; Ebrahim, Barer, & Nouri, 1986). However, Wyller et al. (1998) found that better well-being is associated with older age. This disagreement may be linked to how HRQoL is conceptualised and measured in these studies (Hilari, Wiggins, et al., 2003), as life satisfaction was employed for the former studies, but QoL was perceived as overall health for the latter. Another factor is the severity of the stroke, for which it was found that the worst initial stroke severity is associated with poor HRQoL outcomes (De Haan et al., 1995; Neau et al., 1998; Osberg et al., 1988).

An additional factor is gender, and to date no significant gender effect on HRQoL has been found in the majority of studies on patients after stroke. However, Wyller et al. (1998) found higher subjective well-being in women but did not provide any explanation for this result. On the other hand, HRQoL was found to be worse for women by Carod-Artal et al. (2000), but it was acknowledged that the women in the sample were older at the time of the stroke than the men.

Few studies have investigated the effect of socio-economic class (SEC) and educational status on HRQoL after stroke. Of those which have, Ahlsjö et al. (1984) found that socio-economic class had no effect on HRQoL in their stroke patients, yet King (1996) found that there was a positive association between SEC and HRQoL in long-term stroke survivors. For educational status, poor QoL post-stroke has been associated with lower educational status, and vice versa (King, 1996; Neau et al., 1998).

## 1.9 QoL and aphasia

Over the last ten to 15 years, the evidence around the QoL of PWA has grown steadily (Cruice, Hill, Worrall, & Hickson, 2010), with the finding that aphasia has a negative impact on QoL. According to Bakheit et al. (2007) “Aphasia has a significant negative impact on the patient’s well-being, independence, social participation and quality of life and is often associated with severe depression” (p.885). According to Worrall and Holland (2003), there is no agreement on the extent of this impact, which has been considered as individual variations in most of the studies. For example, Hilari and Byng (2009) suggested that HRQoL may, in PWA, be affected by “their emotional well-being, the severity of their communication disability and their activity levels” (p. 194). Indeed, one recent study by Lam and Wodchis (2010) found that aphasia had the largest negative relationship to HRQoL, followed by cancer and Alzheimer’s. Their study, controlled for demographic variables, considered HRQoL in an Ontario hospital-based long term care population, whilst other studies have focused more on the general population.

According to McColl, Meadows, and Barofsky (2003), measuring QoL for PWA is difficult because these measures usually require the ability to read and understand the questions involved, make a judgment and then choose a response from the different options available. However, various issues require consideration for meaningful conclusions to be drawn from the literature. There are measurement issues, such as the exclusion of PWA in some studies (Clarke, Badley, Lawrence, & Williams, 1999; Duncan et al., 1997; Jonkman et al., 1998), the use of proxy respondents with PWA (Aström et al., 1992; De Haan et al., 1995), and the issue of analysing the proxy findings as reported HRQoL alongside self-reported findings, where the HRQoL is widely regarded as a subjective concept.

Many studies of QoL in stroke and other acquired brain injuries have excluded the PWA from the data collection process in favour of proxies. This is because most of the QoL measures used self-report questionnaires which the participants were required to complete in written form, despite the fact that it is not possible for PWA to respond easily due to their communication difficulties. Nevertheless, to enable PWA to participate directly in the assessment of their QoL, some studies have made appropriate modifications to these measures in order to be able to ask the PWA to complete a questionnaire. To this end, techniques such as simplifying the questions and response format, visual cues, and prompts were used, in addition to the direct interviewing of PWA. All of these techniques

are helpful to enable the PWA to provide valid responses to QoL surveys. They show that when careful attention to the communication problem is taken into account, PWA can reliably report on their personal QoL (Worrall & Holland, 2003).

The use of proxies to report QoL in PWA and not the PWA themselves is one of the most problematic issues in assessing QoL for PWA. The complexity of measuring QoL is exacerbated for those PWA who have language and speech difficulties, which are usually severe. According to Hilari, Byng, Lamping, and Smith (2003), “Although a number of stroke-specific quality scales have been developed, most excluded stroke survivors with aphasia and/ or cognitive decline, subjects most prone to social isolation and exclusion” (p. 1944). For this reason, people with severe aphasia are usually excluded from QoL studies and replaced by proxies, who are usually their spouses, care givers or family members, and so the patients’ viewpoints are not heard. According to Engell, Hutter, Willmes and Huber (2003), the proxy approach (i.e. the use of care givers, family members or significant others) to answer questions on behalf of the PWA still lacks validity, and is exacerbated by the lack of agreement on what type of QoL measure is most appropriate for PWA.

There is debate as to whether the objective or subjective measure is more suitable in some situations, and it may be argued that each type of QoL measurement is appropriate to the purpose and the task of that measure. One reason for this is that the findings in the literature generally suggest that there is weak agreement between PWA and their proxies concerning subjective items in QoL measures, while there is better agreement on objective items of QoL. Moreover, there is a tendency to overestimate the disability that the patient has, depending on the patient’s age and the time spent with those patients (Cruice et al., 2005).

Two studies have reported on the use of proxies and the level of agreement with the patients themselves. Sneeuw, Sprangers, and Aaronson (2002) reported in their comprehensive review between 1990-2000 of 23 QoL studies of chronic diseases, such as cancer and stroke, that there was generally moderate to good agreement between patients and their proxies. This agreement was better in regard to physical domains and lower for psychosocial domains. The results of the study of Cruice et al. (2005) comparing family and friends’ ratings of the QoL of their partners of PWA concluded that the views of the significant others (proxies) were not interchangeable with the views of their

partners with aphasia, and they rated their partners' views of QoL and HRQoL much lower than their partners actually did. It therefore seems that the proxy respondents demonstrate a significant systematic negative bias in rating their aphasic partners' global QoL, physical abilities, and general health, but conversely these proxies rated statistically the same as their aphasic partners on physical fitness, feelings and QoL, and total well-being and purpose of life with at least moderate agreement. Similarly, in other literature there was a generally higher agreement for objective domains than subjective domains. In addition, Cruice et al. (2005) have noted that a number of aphasia studies demonstrate that PWA are potentially biased by their proxies when reporting on QoL in regard to disability, and social and emotional health. Therefore, the impact of such biases should be considered when conducting QoL studies. Unsurprisingly, the difficulty of separating the patient's and carer's views, along with the influence of the latter, has resulted in the use of proxies being criticised (Jordan & Kaiser, 1996). However, the use of proxy raters can prevent the exclusion of severely affected patients and avoid systematic bias (Pickard, Johnson, & Feeny, 2005).

In this context, the views of PWA have become a priority for researchers when developing a measure for QoL. According to Worrall and Holland (2003), measuring the QoL for people with severe and global aphasia is a major challenge which requires a creative study on how to obtain these people's opinions, so they called for the views of people with severe aphasia to be involved in more studies of QoL. Gill and Feinstein (1994) suggested that the most suitable method of measuring QoL was to evaluate the opinions given by the patient, and to replace or add the measures developed by experts. According to Marquis and Jackson (2000), many researchers have recommended extracting information about QoL experience from people with disabilities from the people with disabilities themselves, in order to obtain their insight and recognize the nature of their experience, so that their individual preferences can be valued and supported. This trend is encouraged by many researchers, according to Cruice et al. (2005), who note that "recent research undertaken by speech language pathologists showed that PWA were competent in reflecting on their QoL and participating in research" (p.112).

Different measurement approaches can be seen in the assessment of HRQoL in general, and in stroke and aphasia assessment in particular. The measures employed include a single visual analogue scale (VAS) (Duncan et al., 1997; Kwa, Limburg, & de Haan, 1996), a questionnaire-based interview (Gresham et al., 1979; Lawrence & Christie,

1979), generic scales, such as the Nottingham Health Profile (Wilkinson et al., 1997), the use of battery assessments (Angeleri, Angeleri, Foschi, Giaquinto, & Nolfi, 1993; Sarno, 1997), and qualitative methodologies, such as interviews (Le Dorze & Brassard, 1995; Parr, Byng, Gilpin, & Ireland, 1997). Such issues should be considered in regard to the applicability of these results to PWA, their usage in different settings, and the drawing of comparisons between PWA and others. Also, there is the issue related to the concept of QoL, which in some studies has been expressed as life satisfaction (Ahlsjö et al., 1984; Aström et al., 1992) or subjective well-being (Niemi et al., 1988).

There are two main modes of administration for questionnaires used in QoL measures, self-administered and interviewer-administered questionnaires, with the former usually tending to produce less information than the latter (Buck et al., 2000). An interviewer-administered questionnaire may also detect a higher rate of dysfunction than self-administered ones (Anderson, Bush, & Berry, 1988; Kaplan, Anderson, & Erickson, 1989). Therefore, it allows for an opportunity to clarify misunderstandings and elaborate the meaning of questions, and it also enables observations to be carried out during the administration of the questionnaire. It is an appropriate means for participants with reading or language difficulty. A further means of achieving good quality data with a very good response rate is the mode preferred by Kaplan, Sieber, and Ganiats (1997), who found that non-completed rates were significantly higher for self-administered questionnaires than interviewer-administered ones because of the risk of more missing data.

Furthermore, there is the issue of the relationship between language improvement through therapy programmes for PWA and QoL, with many researchers suggesting that other factors may relate more strongly to QoL (Cruice et al., 2005; Hilari, Wiggins, et al., 2003; Ross & Wertz, 2003). This includes communication ability, which is directly related to aphasia, social relationships and participation, emotional distress, involvement in activities, and environmental aspects. Another issue regarding QoL in aphasia is that the role of the speech language pathologist (SLP) in improving QoL is still not clear, in spite of its importance in the rehabilitation of aphasia. This is partly because it is difficult for the SLP to determine how much of the reported QoL of a PWA is directly related to the aphasia itself, but also because it is unclear what the role of the aphasia is in other domains that are not directly related, such as physical disability.

In conclusion, it can be said that in spite of the growth in studies exploring HRQoL and the related outcomes of HRQoL measures of PWA and stroke, there are some conceptual and methodological issues that make it difficult to form a clear picture of the HRQoL of PWA, and the factors affecting it (Cruice, Worrall, Hickson, Hirsch, & Holland, 2000; Hilari, Wiggins, et al., 2003) and its impact in the therapy programmes.

### **1.10 Sociological background of QoL**

In the research literature on chronic diseases, a person's QoL is usually described by how he/she copes when suffering from chronic, unclear and declining illness. This can be seen, for example, as a discussion of adjustment or adaptation to a disease which tends to be the focus for social health psychologists (Nicolson & Anderson, 2003).

QoL has also been discussed more sociologically in the sense of the relationship of the individual's body, identity and society and the ways in which he/she continues to exchange their relationship with society from the perspective of a person who is no longer able to fulfil his or her social functions (Bury, 1991; Charmaz, 1995). According to Marquis and Jackson (2000), recent research on QoL has moved its focus to the meaning of 'quality of life' for people with disabilities as it is reflected in their sense of self, personal efficacy, belongingness and relationships with others.

QoL measures take account of factors such as physical functioning, social functioning, limitations, general health perceptions, the impact of symptoms, and mental health in a different way. Sociologists such as Williams (1984), Williams (1989) and Bury (1991) have variously identified the complex interrelationship between the individual, his/her illness, and the social context in which s/he lives. Also, Williams (1984) argued that the chronically ill person tries to establish a valuable/functional purpose in relation to his/her body, the illness, society and his/her self. Charmaz (1983) argued that in a society where the focus is upon competence and social obligations and commitments, the person who is incapable of coping with their responsibilities loses the resources needed to sustain a meaningful life in that context. Thus, such individuals engage in a process whereby they 'disgrace' themselves by adopting the shared societal beliefs about being 'fully functional'.

Thus, QoL in this context suggests that there is an active relationship between the individual and the society through which subjective interpretations of QoL are understood.

This includes the experience of attributing a meaning to the illness and the way of life, in the context of that illness in the society in which the illness ‘takes place’.

Such individuals are fully engaged in this relationship both in terms of observing and trying to understand the physical changes and evaluating themselves as a person and member of society accordingly. Given this dimension behind QoL, it would stand to reason that QoL is a part of the function of the society in which the person with the illness returns, where the community support within is clearly likely to affect the individual. This leads to the importance of understanding the nature, features and characteristics of the community and what this means for the wellbeing of people with disabilities and with aphasia in particular, where the language function is important to their own wellbeing, positive relationships with others, and self-acceptance (Cruice, Worrall, Hickson, & Murison, 2003).

### **1.11 QoL in Arabic countries**

Most of the available evidence about assessing QoL in general, or in relation to a particular disease or condition, has been gained in western countries which are predominantly Christian. A limited number of studies have been done on QoL for certain conditions in Arabic countries, using direct translation of an assessment tool without cultural adaptation. However, the drawback with the direct translation is that it makes generalization about the Arabian culture difficult, as this culture is defined by the important role that Islam plays in all aspects of people’s lives (Rashidi & Rajaram, 2001) and this is not reflected in these measures. Moreover, no studies have been found on people who have experienced aphasia in the Arab culture.

In the literature, QoL measures in Arabic countries have been found for generic QoL and QoL specific to a certain diseases or particular conditions or age groups, and most of them are administered in English, or translated or adapted into Arabic (Bowden & Fox-Rushby, 2003). Some of the generic measures have been translated into Arabic and used with Arabic speaking populations, but there is insufficient information about the quality of these translated or adapted measures, or about the measurement properties after adaptation. This information is essential in the selection of a particular generic measure for HRQoL for Arabic speaking people (Al Sayah, Ishaque, Lau, & Johnson, 2013).

In a recent study by Al Sayah et al. (2013), a systematic review was conducted of twenty studies from six databases, to identify generic HRQoL measures such as Medical Outcomes Study Short Forms (SF-36) (Ware, Kosinski, Dewey, & Gandek, 2000), Health Survey (RAND-36) (Hays & Morales, 2001), the World Health Organization Quality of Life Brief version (WHOQOL-Brief) (WHOQoL Group, 1998), the Dartmouth COOP Functional Health Assessment Charts/World Organization of Family Doctors (COOP/WONCA charts) (Van Weel, König-Zahn, Touw-Otten, Van Duijn, & Meyboom-de Jong, 1995), the Euro QoL Group health status index 5-Dimensions (EQ-5D) (Rabin & Charro, 2001) and the Quality of Life Index (QLI) (Ferrans & Powers, 1985). All of these were translated into Arabic to evaluate their cross-cultural adaptation and measurement properties. According to this overview of the 51 studies involving the use of these measures, the SF-36 was the most commonly used HRQL generic measure in the Arabic-speaking population (22 studies), followed by the WHOQOL-Bref (19 studies), COOP/WONCA charts (four studies), EQ-5D (three studies), RAND-36 (one study), and QLI (one study). The study revealed that there is limited available evidence on the performance of each of these identified measures. It was noted that the evaluation of the cross-cultural adaptation of the measures was limited due to the lack of detail about how researchers translated a particular measure. Also, the large differences in Arabic language and culture-specific idioms across countries makes it challenging to transfer these translated versions from one Arabic country to another, or to apply them in different Arabic speaking populations. In addition, they concluded that the use of each of these instruments should be based on the target population in a particular study, and how much this population is similar (in terms of language and culture) to the population for whom the instrument was adapted. Also, it revealed that it is clear that research on HRQoL in Arabic countries is scarce and the authors stressed the need for further investigation in the field of HRQoL and its measures. Thus, it can be said that growth in the field of HRQoL measurement in Arabic countries is slow in regard to the translation, adaptation and application of the Arabic version of these measures (Al Sayah et al., 2013).

A limited number of studies have also been carried out on the relationship between religion and subject well-being using Arab and exclusively Muslim participant countries, such as Saudi Arabia, Kuwait and Algeria (Abdel-Khalek, 2006, 2010a, 2010b; Abdel-Khalek & Lester, 2007). For example, the study by Abdel-Khalek (2010a) explored the associations between QoL, subjective well-being (SWB) and religiosity, which is viewed by Giaquinto, Spiridigliozzi, and Caracciolo (2007) as shared doctrinal beliefs and

participation in certain behaviours. This was in an Arabic society with a Muslim sample of 224 Kuwait University undergraduates aged 18-28 years old. This study was carried out by applying the Arabic version of the World Health Organization's QoL scale-brief (WHOQoL-Brief), along with six self-rating scales of physical and mental health, happiness, life satisfaction, religiosity and strength of religious belief. Based on the significant and positive correlations between QoL, SWB and religiosity, it was concluded that religiosity may be considered a significant component of, and a contributing factor to, QoL for this sample. There were other possible components for this association, such as different gender roles; these differences were indicated as men in Arab countries having more freedom than women, particularly in Kuwaiti society, which is described as a religious, collectivistic and conservative society (Abdel-Khalek, 2010). Moreover, Islamic beliefs and practices may have the potential to be integrated into the psychotherapeutic procedures of Muslim clients. The two main results of the above studies were, first, that there is a positive relationship between religiosity and SWB, life satisfaction, physical and mental health and happiness. The second result was that there is a negative relationship between religiosity and anxiety and depression, and therefore it can be said that religion has a role in relation to QoL which needs to be investigated, especially in Islamic culture. However, it should be noted that these studies were done on young, healthy college students and adolescents.

A recent study by Tiliouine, Cummins, and Davern (2009) used an Islamic religiosity scale, constructed for the purpose of the study, with 2,909 Muslims from Algeria; it found that people with high scores of personal well-being recorded high scores on religious practice. This study was also conducted mainly on healthy participants; about half of them were aged between 18-25 years, as only 2% were 56-plus years old. Although these findings cannot be generalized to include PWA, they do provide a general picture of the association between religion and QoL in an Arabic and Islamic culture.

In the literature, there are number of studies of QoL in Arabic culture for specific diseases or with a specific population. Examples are people with schizophrenia (e.g. Al Showkan, 2012; Zahid et al., 2010), with haemodialysis/dialysis patients (e.g. Al-Jumaih, Al-Onazi, Binsalih, Hejaili, & Al-Sayyari, 2011; Ayoub, 2012), with patients of breast cancer and gynaecological cancers (e.g. Awadalla et al., 2007), and with diabetic patients (e.g. Al-Shehri, Taha, Bahnassy, & Salah, 2008; Amer, Alsadany, Tolba, & Omar, 2013). Other studies were conducted in an Arabic community but not in Arabic culture (e.g. Mustapha,

Hossain, & Loughlin, 2014; Zakarni, 2013). Furthermore, other studies for QoL have been done for an Arab general population (e.g. Ohaeri & Awadalla, 2009). It should be noted that the measures used in such studies on QoL for specific disorders were directly translated, such as the Lancashire QoL Profile –European version (LQoLP-EU) in Al Showkan's study, and the Kidney Disease QoL Instrument Short Form (KDQoL-SF) in the study of Al-Jumaih et al. Similarly, direct translation was done for generic measures in the studies of Ayoub (generic version of QoL Index), Awadalla et al. (WHO-QoL-Bref) and the Short Form 12 (SF-12) in the study of Amer et al.

### **1.12 Arabic culture and the context of the study**

From the literature, according to Tiliouine et al. (2009), the relationships between different forms of faith or belief and the generic concept of QoL have attracted considerable research attention. For example, Sawatzky, Ratner, and Chiu (2005) found 371 publications concerning the relationship between spirituality/religiosity and quality of life, subject well-being, or life satisfaction. Koenig, McCullough, and Larson (2001) reviewed studies that have examined the relationship between religious involvement and measures of well-being, happiness, and life satisfaction. This study is one of the most comprehensive and systematic reviews available on the relationship between religion and health. The authors examined the relationship between a religious variable and selected health outcomes, and they employed several online databases and previously published and unpublished reviews of the literature. 850 studies on the religion-mental health relationship were identified. It was found that almost 80% of the 100 studies that have statistically examined that relationship report a positive correlation, 13% reported no association, and seven per cent reported mixed findings. Only one study found a negative correlation between religiosity and mental adjustment, and well-being, but this study was conducted in a small, non-random sample of university students (p.117).

Therefore, as most studies were carried out in western and Christian culture, it is important to explore the relationship between religion and QoL in Muslim culture and to do that it is important to make a careful distinction between the concepts of religiosity and spirituality. In considering this issue, according to Sawatzky et al. (2005), spirituality refers to the subjective relationship with something that lies beyond the physical, psychological, or social dimensions of life. Spirituality is commonly associated with an existential search for meaning and purpose. On the other hand, religiosity is expressed through predefined behaviours and practices. Thus, religion refers to the objective,

observable customs or prescribed behaviours that receive validation and support from within an identifiable group of people. Spirituality in Islam is the devotion to an identifiable, recognizable God (Allah) who has His descriptions in the holy Quran and the Prophet's teachings (Sun-na). Also, Rassool (2000) points out that in the Islamic context, the terms "spirituality" and "religion" have the same meaning.

As an Arabic country, Saudi Arabia is in the Middle East, where it occupies most of the Arabian Peninsula. The neighbouring countries are Jordan, Iraq and Kuwait in the north and northeast respectively, and Qatar, Bahrain, and the United Arab Emirates in the east. Oman and Yemen have borders in the south west and south respectively. The capital and largest city is Riyadh (Mufti, 2000). The climate of Saudi Arabia is a desert climate which is generally hot and dry in summer and cold and dry in winter (Mufti, 2000). In relation to this study, the climate affects the lifestyle of Saudi people in terms of what they wear, transportation and daily indoor or outdoor activities. Saudi Arabia has a population of about 29 million. Approximately 69% of the population (20m) are native Saudi, and the rest are expatriates. Demographically, 32.5% of the Saudi population is <15 years of age, 64.7% between 15-64 years and only 2.8% are 65 years or more; the general gender distribution of the Saudi population is 100 males: 102 females (Central Department of Statistics and Information, 2011).

Arabic is the official language; however, English is widely used and understood among Saudis in work places and universities, and especially among the younger generation who attend private or international schools and those who have studied abroad. Modern Standard Arabic is only used at the official level, such as in the national media through TV, radio and newspapers, and official communication between governmental and non-governmental bodies. It is also used in school text books but is not used as a spoken language. Classic Arabic<sup>1</sup> is called the language of the Quran (the book of Islam), so the main use of classic Arabic is in reading the Holy Quran, which is mainly in the five daily prayers or reading the Quran directly. The spoken language in Saudi Arabia consists of

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<sup>1</sup>Classical Arabic is also known as Quranic Arabic, which is a form of Arabic language used in old literary texts. It is different from the Modern Standard Arabic in its lexis and stylistics, but the morphology and the syntax are basically the same for both.

regional Arabic dialects, and there are five main dialects according to the five main regions in Saudi Arabia.

Saudi Arabia is an Arabic country in which no other religion than Islam is practised and it is known to be a conservative Arabic culture. However, expatriates are allowed to practise other religions freely in their homes. Saudi Arabia is considered the home land of Islam, as it was here that the prophet Mohammed (peace be upon Him) founded Islam; it is also the location of the two holy cities for Muslims, Makkah and Medina (Al-Khateeb, 1998). The implications of religion for this study are discussed in more depth in the section below.

Saudi Arabia is a monarchy and the legal system in Saudi Arabia is based on Islamic law (Sharia law). This Islamic law is both the source of monarchical authority and the basis of the country's conservative, traditional customs and social practices (Gallagher & Maureen, 1985).

### **1.13 Stroke and aphasia in Saudi Arabia**

There is limited information about the incidence and/or prevalence of stroke and aphasia in Saudi Arabia. Benamer and Grosset (2009), in their systematic literature review study about stroke in Arab countries, from 31 articles from 23 different Arab countries, 16 articles were from Saudi Arabia alone. The publication dates in this study ranged from 1983-2008. This review was undertaken to provide a background for designing future stroke studies in Arab populations. Many of the Arabic studies in this review are 10-20 years old, which indicates that up-to-date figures of stroke epidemiology in the Arab world are therefore scarce. This review shows a lower incidence of stroke in Arab countries, which continues even after age adjustment, when compared to the more developed countries. Also, the available data suggest that stroke type and risk factors found in stroke patients in Arabic countries are generally similar to the developed world. This review indicated that the relatively younger population in Arab countries means that future studies require age correction; only 3.4% of the population of Libya, and 3% in Saudi Arabia are over 65 years of age, which contrasts with 16% in the UK and 12.5% in the United States of America.

In this review, stroke incidence varied from 27.5 per 100,000 population per year in Kuwait to 63 per 100,000 population in Libya, to 43.8 per 100,000 population per year in

Saudi Arabia. In addition, the overall prevalence reported in Saudi Arabia was 186 per 100,000 population. This review concluded that “the significant recent and ongoing socio-economic changes in Arab countries, including increased life expectancy and greater adoption of a westernised lifestyle, especially in the Gulf states, raise the likelihood of an increased stroke rate” (p.22).

Although there is limited published information available about the incidence and/or prevalence of stroke and aphasia in Saudi Arabia, either from the Ministry of Health or other related governmental bodies (Yaqub, Shamena, Kolawole, & Patel, 1991), a valuable review of stroke incidence and prevalence was undertaken by Al Rajeh and Awada (2002). This study assessed ten years of research covering more than 25 publications about stroke in Saudi Arabia. In this review, the authors indicated that stroke patterns and types of stroke are not very different in comparison to other developing countries, but, in contrast, the incidence and prevalence of strokes reported in Saudi Arabia were low, where the crude incidence of first stroke is extremely low at 25.2-34.3/100,000/year compared to 150-250 new cases/100,000/year in western countries and Japan, and the prevalence of stroke to be 186/100,000 compared to (600-800/100,000). This is one fourth to one third of the commonly reported prevalence in western countries, which again reflects the impact of age in comparison to western countries. The study also reports that men are more likely to have a stroke than women, as men comprise 67% of stroke patients. Nevertheless, further research in this area is required because these findings refer to the current, younger population. They also relate the relatively high frequency of strokes among this young age group to cerebral haemorrhage disease (arterial hypertension) and the high prevalence of diabetes mellitus as risk factors.

This review provides a better picture of the magnitude of the disorder and risk factors in Saudi Arabia, which can be used as a basis for future research, despite the fact that it is a study limited to hospitals. This means that mild and non-hospitalised cases have been missed, and that the work mainly employed a retrospective method to collect the data. Also, the information is linked to specific geographic areas (eastern province), and so other areas have been neglected; it does not therefore represent the whole population.

Another earlier study by Awada and Rajeh (1999) on the analysis of the first 1,000 cases of the Saudi Stroke Databank indicated that in Saudi Arabia community-based epidemiology studies on stroke rarely provide the best data about the incidence and

prevalence due to the lack of diagnostic criteria used. Therefore, hospital-based stroke databanks are used to provide complementary information in this regard, relevant to the diagnostic and management information for patients with stroke. Also, their study confirmed that stroke in younger age groups was common in the Saudi environment, where 15.9% of their patients were younger than 45 years at stroke onset as compared to 3-5% in western epidemiological studies. In addition, males comprised the majority only after the age of 40, but before this age the male/female ratio was 1 to 1, and became 2.16 to 1 in older age groups.

Al Rajeh, Awada, Niazi, and Larbi (1993), in their study of stroke in Saudi Arabia and analysis of 500 cases from a population-based hospital in the National Guard community, argued that the age-adjusted rate could not be calculated due to the lack of basic demographic data from that population. This was supported by Qureshi (2007), who noted that in Saudi Arabia studies on the exact incidence of stroke are rarely carried out and so the data are poorly established. Also, most of these studies were done on a regional not national level.

In addition, there are no published statistics or epidemiological studies on aphasia in Saudi Arabia. In general, it can be said that in Saudi Arabia there is a lack of data on various aspects of the health of the elderly, and those studies which are available are hospital-based, which limits the extent to which the health situation of the elderly has been described (Al-Shammari & Al-Subaie, 1999). Moreover, despite the main governmental hospitals in major cities having stroke units, often under the neurology department, and providing distinguished services for stroke with a 24-hour emergency service, there are no protocols, procedures or guidelines at the national level to manage and coordinate between hospitals and stroke units in regard to the services provided for stroke patients, or for PWA.

#### **1.14 The reflection of religion in Saudi PWA in relation to QoL**

The different culture and religion of Saudi Arabia may result in an experience of aphasia due to stroke that is different from those reported in other parts of the world, leading to a different view of QoL. It is therefore possible that Saudi PWA have different expectations, for example by becoming more faithful believers and more satisfied with their lives post-stroke.

Just as health is viewed as a comprehensive “package” involving interaction between cultural, social and philosophical factors, and not only the absence of disease (Miller & Thoresen, 2003), so, in regard to QoL and how the Muslim patients cope with health problems to improve their QoL, it has been reported that religious coping, such as performing prayers to help ease the burden of sudden disability, is used by Muslims more than other cultural and religious groups of people (Bhui, King, Dein, & O'Connor, 2008; Loewenthal & Cinnirella, 1999; Loewenthal, Cinnirella, Evdoka, & Murphy, 2001). There are some essential religious issues which affect a Muslim’s life and any change in these issues will have an impact on their life and how good or satisfactory QoL is received as Islam is the core of their lives. This perspective explains the importance of Islam to QoL, and it will now be explored for Saudi PWA, in more depth.

#### ***1.14.1 Basic principles for Muslims in Islam***

In Islam, there are two sources of behavioural norms and social acts commitments; the first is the acceptance of the Quran as the ultimate source, and the other is the prophet’s sayings, actions, deeds and explanations (Sun-nah). These two sources guide the Muslim’s daily life practice, and the whole life of a Muslim is controlled by Islam in all spiritual, social and political aspects. This effect can therefore be seen, for example, in Muslims’ prayers, supplications (Duaa), greetings, way of washing, eating, clothing and dressing, relationships, and interactions with others within the family and the society (known and strangers), participation in occasions such as marriage, birth, sickness and death, charity to the poor, and even their relationship with their ruler.

The five fundamental pillars in Islam denote what the Muslim should do to be a Muslim.<sup>2</sup> Prayer and fasting are the two pillars that most affect a Muslim’s health and life. In Islam, there are two types of prayers, the obligatory prayer, which is the second pillar, must be done five times a day at a certain time (one before sun rise (dawn prayer), and at noon, midday, sunset and night). For Muslim males, these prayers should be done in the Mosque

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<sup>2</sup> The five pillars are: first, the testimony of the unity of God (Allah) and the Prophet Mohammed as the messenger of God (Al-sha-hadah); second, prayer five times a day (Salah); third, charity giving to the poor (Zakat); fourth, fasting during the month of Ramadan (the ninth Arabic month of the solar calendar); fifth, performing (Hajj) the pilgrimage to Makkah (Rassool, 2000; Sutherland & Morris, 1995).

(Masjid) with a group of Muslims (Jama-ah), as long as they are within the civilization; otherwise, it can be done individually. On the other hand, for female Muslims these prayers are performed at home, either individually or as a group. The second type of prayer is a voluntary one, and is not a pillar; it can be done at any time of day or night, not necessarily at the Masjid, for both genders. All these prayers should be preceded by a prescribed ablution, for which there is a set of steps to follow. This ablution is called (Wadou), meaning washing and purifying the Muslim from bad deeds and acts (Rassool, 2000).<sup>3</sup> In this way, the ablution involves different physical movements of hands and body, and so requires good physical ability.

Prayer itself involves a certain physical positioning of the body (including standing, kneeling, bowing, sitting and prostrating oneself to God in the direction of Makkah). It also demands a kind of communicant modality, such as the recitation (reading) of verses of the holy Quran that are learned by heart and the repetition (saying) of some phrases that are spoken when changing positions during, and at the start and end of the prayer. This is different from prayer in the western view, which means talking to God privately. Those people who are unable to perform these prostrations are allowed to pray in a seated position or in a chair, on one side of the body or lying back in bed. If this is not possible because of the severity of their condition, they are allowed to pray according to their current status and what parts of the body they can move. There is a rule in Islam which is that if health is threatened, obligations are removed.

One of the ways in which a Muslim expresses their satisfaction with life is in their ability to perform and fulfil as many as possible of the basic principles noted above. In spite of the fact that a Muslim is exempted from doing such duties and responsibilities in life threatening times, they may still feel that they are not doing well or enough to satisfy God, which is the ultimate goal for the Muslim. For this reason, any failure in these principles may affect their view on life, and whether it is a good or bad life.

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<sup>3</sup> This ablution includes washing different parts of the body with water starting with cleaning the private parts, then cleaning hands to the wrists, mouth rinsing, nose blowing, face, hands again to the elbow, head from front to back, ears, then feet to the ankles (Sutherland & Morris, 1995).

### ***1.14.2 Modesty and gender differences***

In general, in relation to conservative norms in Islam, men and women are allowed to interact socially only when they are family members or relatives. There are also some specific requirements concerning the covering of the body for women and men in the presence of non-family members, who are considered strangers (Hammoud, White, & Fetters, 2005). In addition, exposing one's skin to the opposite gender is not allowed for both sexes, so it is considered immodest behaviour for both males and females when short clothing or clothes that expose flesh are worn.

In Saudi Arabia, these issues should be closely considered when, for example, examining the opposite sex in a hospital setting, where a same sex health provider should be available or the attendance of another member of the same sex is needed. This also applies when somebody's private parts need to be exposed, such as in the case of sickness or inability to clean oneself. In Islam, these norms are only removed for emergencies or life threatening situations. Keeping this in mind, there are considerable differences in regard to the issue of interaction between men and women in Arabic Muslim countries. These variations are based on different explanations of Islamic directions in this regard. These principles play a major role in the religious aspect of the Muslim's life and how he/she shares these beliefs and practices with other Muslims in the community. These principles and issues will be considered when developing the questionnaire/scale, and its appropriateness and accessibility for the Saudi PWA.

In regard to this issue, both male and female Muslims feel guilty when they break such rules or boundaries, even if involuntarily. For PWA, this makes their life more difficult, especially when they feel that they have committed a sin, but also when they think about how others who do not know about their real health problems might question their commitment to their faith.

### ***1.14.3 Present and future perspectives in the Muslim's life***

There are different perspectives on destiny and the future in a Muslim's life. One perspective is that a Muslim depends on God (Allah) in his/her daily life activities and actions. A Muslim should accept whatever happens to him/her, either good or bad, as it is from God and is a condition of being a Muslim. This dependency on God is a basic aspect that can be explicitly seen in the intensive use of the phrase (In sha-Allah), which

means (if God wills it) in almost every matter in the Muslim's life that is linked to something in the future, either great or small, and simply means that one's future is in the hands of God. Muslims depend on God in this sense, meaning that what will happen in the future is under God's protection and supervision. They believe that, whatever happens, there will be something good for them at the end, even if it seems not to be so at the time. It is God's decision or destiny for events to happen in a certain way, so they should be accepted by saying the phrase 'this is God's will.' All life incidents from birth to death are written on the preserved tablet, but the Muslim still investigates and examines the reasons and the causes of why this event happened.

Another perspective is that Muslims feel that they are watched by God all the time and in all places, and they cannot hide from God. On this basis, they will be rewarded for their good deeds and punished for their bad ones, and accordingly if a Muslim commits a sin, he/she will be afraid of God's punishment, whatever the punishment is. Therefore, he/she asks God for forgiveness by repentance, doing good deeds and giving charity, fearing God's punishment in the future. Any hardship or trouble that a Muslim faces, such as sickness or loss, is interpreted as God's payback for any wrong behaviour that the person has committed (Athar, 1993, 1998). On the other hand, this interpretation is combined with the belief that when the Muslim becomes ill or has a chronic disease, or is depressed (poorly motivated) or is just sad or has even just been pricked by a thorn, this is considered a purifying and cleaning procedure from God to his/her soul for any sins committed (Rassool, 2000). This is based upon many of the prophet's sayings in this regard, and it is not only viewed as a punishment, but as a reward, blessing and mercy from God from another perspective. Another interpretation of any hardship the Muslim experiences is that it is a test from God for his/her patience and faith in God's destiny, which reflects the strength of his/her faith (Al-Jibaly, 1998). From this, it can be concluded that any kind of hardship the Muslim faces should be accepted and he/she should be patient and not object to God's destiny. In the light of the importance of this issue, there was a clear need to consider it when developing the questionnaire in relation to aphasia as a disease, and how the PWA views it.

This aspect of accepting destiny in the Muslim's life is reflected and shown in his/her satisfaction with life, either good or bad, without complaining. Also, it is expected that patients should thank God for his mercy and for the other blessings in their life.

#### ***1.14.4 Marriage and private life***

Marriage is viewed as the basic unit of the Islamic society and is strongly encouraged and valued. Although divorce is permitted in Islam as a necessity, it is discouraged and the marriage is protected as the last option for keeping the unity of the family for the sake of the children. In relation to this study, sexual dissatisfaction can be considered fair grounds for accepting a women's request or petition for divorce, and the same is true for the man, who can either obtain a divorce based on the same grounds, or marry other women. This can occur, for example, when one of the couple has a chronic disease which might prevent them from enjoying their private life or having children. Divorce in this case will protect the husband and the wife from seeking satisfaction outside the marriage. The same is applicable in regard to self-caring when the partner cannot take care of their own basic needs.

The issue of having a chronic disease is critical in the Muslim's life, and is more so for such patients. For example, a wife who has a chronic disease will feel insecure about her life as the husband may marry another woman as his right. In cases where the patient is the husband, he also will feel that he is not good enough as a man for his wife, and also that he has lost the voice of authority in the family. Thus, the strength of the marriage, personal relationship and the family will be under pressure all the time, and can have an impact on the patient's view of life.

#### ***1.14.5 Parents and their role in a Muslim's life***

According to Islamic norms, obeying one's parents and taking care of them is a must and disobedience or neglect of them is a great sin. Furthermore, obeying parents is considered a part of obeying God and the blessing of God is linked to parental blessings. It is a lifelong commitment which comes first over all other social relationships, even before marriage, and it is a commitment that becomes stronger as the parents become older. In relation to PWA due to stroke and QoL, the patients who are parents face the problem of how they are treated by their children after the incident. This treatment of the parents influences their views on life, and so they consider themselves lucky when they are well treated and blessed by God for having obedient children who take care of them. It is considered to be one factor which makes them happy and satisfied with life to have such children, while it is considered the opposite when they are neglected by their children and feel that their role has ended when they are unwell in old age.

## 1.15 The reflection of the Arabic culture on Saudi PWA in relation to QoL

### 1.15.1 *The family structure*

As in any other Arabic country, family is a very important element (Nyrop, 1984), as it is the first circle of the person's social life. In general, the Arabic person is very attached to his/her family and family is the basis of identity for the individual, especially in a tribal society like the Saudi, in which a person is still recognized by their tribal affiliation.

Similar to many eastern and western societies, Saudi family is a cornerstone in the society. In places where the traditional Arab norms are mostly undamaged, such as in rural areas, the extended family type is still found, but not as widely as before (Al-Khateeb, 1998). In this way, two generations of the same family can be found in one household called the family house or the big house.<sup>4</sup> In this system, Saudi parents, as fathers and mothers or as grandfathers and grandmothers, are always under the care of their descendants when they become older or when they are ill. The other type of family is the nuclear family of the father and mother and their own children. This type is commonly found nowadays in large cities and urban areas, as an effect of modern civilisation (Al-Khateeb, 1998). In general, however, in Saudi Arabia a person's loyalty to his/her family is a very important obligation of social life. These family relationships usually determine the person's relationship and status as an acceptable member of the family for other relatives of the same family, or within a larger circle in the community.

From the broader Islamic perspective, family in Saudi culture and parents, in particular, are the centre of social life. It is viewed as an honour that you keep your parents with you when they become old and take care of them, and it is seen as a blessing to your family

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<sup>4</sup>The family house or the big house is where the father and mother, their sons and their wives, daughters, and their grandchildren from their son's side live. These family members usually consist of the blood relatives of the grandfather, who is the head of this family.

and your own home, while it is unacceptable and shameful behaviour to place your parents in a nursing home or bring someone such as a housemate to take care of them while you or your wife or children can care for them; to do so loses others' respect (Al-Shammari & Al-Subaie, 1999).

From an early age, children are taught to obey and respect their parents and the older people in the family, and to take care of them, keeping in mind the saying that what you do for your parent, your children will do for you later. Thus, it is common to find people rushing to take care of their parents by themselves without help, especially when their parents are old or sick, and even when their needs are private, such as taking them to the bathroom or cleaning them (son with father, and daughter with mother). From this, we can see that in Saudi culture elders, especially the parents in the family, have a great value and are due more respect than younger ones; these elderly people are respected for their age, their knowledge and their wisdom.

Because of these social norms of the Saudi society, it can also be said that family is an important factor in the life of the Saudi people. The change in the position and role of the person in the family has an impact on his/her life. That is, their value within the family (nuclear or extended) because of having such a chronic disease will influence their view of life. Patients usually judge their relationships within their own family members and the respect shown to them, and so to have a family that is supportive and encouraging in such a situation is crucial to the patient's view of their life, as life satisfaction can be expressed by having a caring and supportive family. Therefore, any change to their value in terms of their role, care, respect and dignity will affect their views on life.

### ***1.15.2 Views of chronic illness and treatment***

It is worth looking at the religious explanations of illness and diseases, as for Muslims life is seen as a test of faith and illness is seen as part of this test, and ill health is seen as predestined by God. In Orthodox Judaism, it is believed that nothing happens without God, so illness or disease are therefore seen as God-given, and may be the way in which God punishes an individual for wrong-doing. Christians have two views on this aspect; the first believes that God has absolute control over our lives, and the second is that suffering is seen as an opportunity for spiritual growth (Yamey & Greenwood, 2004). Thus, it can be said that Muslims, Orthodox Jews and Christians have similar views and explanations about illness and disease.

In regard to humanistic interventions for therapy and treatment, Muslims are strongly encouraged to seek care and treatment (Rassool, 2000). This is also indicated by Al-Ghazzali (1970), who states that illness is one of form of experience through which humans arrive at knowledge of Allah. Seeking treatment for illness is not regarded as a sign of conflict with reliance on Allah for a cure, and treatment is also encouraged by the prophet Mohamed (PBUH) in his saying “Seek treatment, because Allah did not create a sickness but has created a treatment for it except for old age” (Rassool, 2000, p. 1481). Therefore, seeking conventional medical help and praying are seen as complementary rather than conflicting, and those people who are involved in the treatment/therapy are seen as instruments of God.

In Judaism, the central theme of recovery is that nothing can be done in this world without God. The Torah (the book of Judaism) states that God is the healer, but it recognizes that the people provide medical services as God’s agents and partners in the process of healing.

In Christianity, there are many variations in how Christians view recovery, so, for example, those who hold a fatalistic view believe that recovery and healing only occurs if God wills it. Others see recovery as involving factors such as the natural recovery, external medical intervention, the patient’s view of their illness, and their own spirituality (Yamey & Greenwood, 2004).

Thus, in general it can be said that fatalistic ideas about recovery and treatment are shared and expressed by not only Muslims but by Christians and Jews as well. However, clinically, it is important that this generalization should be treated with caution, as all members of one religion are different and so each individual practises his/her religion in their unique way.

Chronic diseases such as aphasia, Alzheimer’s and some kinds of cancer are hidden from others, as the patient’s family may fear that the condition will negatively change peoples’ views of patients and even of their family members, such as decreasing the possibility of marriage connections in the future. It should be noted that, in spite of this, any disease is accepted, as it is from God, but the Muslim should look for the treatment and not surrender to it.

Traditional treatment still exists and is popular in Saudi Arabia in spite of the development of the health services, and so herbal treatment is commonly used, especially

as a first trial for the problem or when modern medicine fails to achieve good results. Another alternative to medicine is religious healing or a remedy which is usually done by a traditional healer (a religious person). This treatment involves recitations of the Holy Quran over the patient (Rassool, 2000), in addition to verbal prayers (supplications) to God for healing (El-Islam & Abu-Dagga, 1992).

To have such a disease, and to see how the society views them, can have an impact on the patients themselves, especially in the way people stigmatize these patients within society as abnormal people and they are not capable as before. This issue will therefore affect their views on life.

### ***1.15.3 Social interaction***

Saudi society is a very active and generous society in its social interaction, as are many Arabic societies (Nyrop, 1984). It is a very emotional society; these emotions appear in the way Saudis interact on both good and bad occasions, where everyone shares their feelings. This can be noticed from the way of greeting, where each person is individually greeted whether they know the person or not, adheres to Islamic instructions on how to greet people. This greeting is usually accompanied by a handshake with the right hand when the person is known to them, bearing in mind that using the right hand in greeting is a must, as per Islamic instructions to use the right hand in greeting, eating and drinking unless you cannot due to injury or illness. Also, using the left hand is considered disrespectful to the other person, as it is not clean and is considered devilish. Hugging or kissing on the cheek on both sides is common on occasions such as births, marriages, the Islamic Eids, deaths and funerals, or when travelling and also when visiting someone ill, and thanking God for his/her safety. These greetings involve both physical acts and speech. Men and women may greet only people from the same sex, and only those of the opposite sex if they are older people who may be considered parents for them, and if they are family members or relatives.

It is a common attitude in Saudi culture to find many visitors from the patient's family, relatives, and friends or people that the patient knows, both during the visiting hours at the hospital and at the patient's home when he/she is discharged from hospital. The family's role in treating illness is essential in Arab and Muslim cultures (Hammoud et al., 2005). This norm comes from Islamic law that encourages Muslims to visit the patient as it is considered a good deed, which will be rewarded. This shows the importance of the

presence of the family and the people in the patient's life in Saudi society, and how they are a good support and strong motive in the patient's recovery from illness.

The daily life in Saudi Arabia tends to be active, and in spite of modern communication technology people still contact each other in person; this is especially true with elderly people and is much appreciated. Generally, the car is the main transportation method as no other public transportation is used, such as metros, trains or bus networks. Women are not allowed to drive, so it is common for the Saudi family to employ a (non-Saudi) driver who is most of the time (non-Arabic). Also, it is common to employ a (non-Saudi) housemaid or domestic helper to do the house work or take care of the children when the wife works. These conditions are considered a necessity when the man becomes unable to drive or the woman cannot fulfil household responsibilities due to illness. However, most of these drivers and housemaids are not Arabic and do not speak Arabic.

Regarding entertainment and exercise, nowadays TVs and satellites are found in almost every house (Al-Khateeb, 1998). As there is widespread internet coverage in Saudi Arabia, the outside world has become known to Saudis, especially through the news. These facilities are considered basics for entertainment and leisure. For men, outdoor exercise such as jogging is still strange and unpopular, and men tend to feel shy about it. For women, exercise is more difficult because of the sex segregation, and because there are very limited facilities where women can exercise outside the house; women who do so are sometimes seen as immodest. Doing such outside activities tends to be more popular among the younger generation rather than the older generation, who consider it disrespectful for their age.

This generational difference that has different aspects such as in entertainments and outdoor activities may be linked to the high level of illiteracy and low educational level prevalent among the elderly in Saudi Arabia, who had their basic education in the Kata-teeb (circles for teaching the Quran and the principles of Islam) in Mosques (Masjids), to learn how to read the Quran and do basic numeracy (Nyrop, 1984). In addition to the lack of community awareness about the importance of physical activities among elderly people, it seems impossible to quantify the past situation of education with confidence due to the lack of census data on educational levels and on age-specific literacy (McHale, 1980).

It should be noted that in the Saudi social structure, there is no categorizing of people according to their income or wealth, although it is well-known among the Saudi people themselves that there are families who are exceptionally rich. Officially, the government itself does not categorize, except for one category which is for people with limited income (people with only one income); this is done to provide them with governmental help and services. Muslims are encouraged to be modest and not feel different from each other because of their wealth, social status, colour or tribe (Rassool, 2000), and for this reason the categories for socio-economic status are not applicable in Saudi society as it is rejected in Islam.

Social interaction is an essential issue in Saudi culture, so the failure in not socialising with others will make the patients feel the extent of their disabilities. This can be seen as attendance at social occasions, and physical greetings become limited, as well as visits to family and relatives. Also, dependency on house maids and drivers reveals the extent of their weakness, which is combined by the lack of outdoor activities for people with disabilities in Saudi society. These issues affect how the patients view their lives, as they become isolated and dependent.

In conclusion, it can be said that the review of the literature has shown how the concept of QoL and HRQoL is viewed and defined from different angles, where no single definition has been found. It demonstrated the different purposes of exploring QoL and the issues related to the generic and specific measures of QoL for PWA. The strong association of aphasia as a result of stroke to QoL and the factors involved were shown by this review. It also illustrated the different approaches and aspects of measuring QoL for PWA such as proxy usage and communication difficulties. This review has shown the limited literature found in Arabic countries in regard to QoL measures both in general and specific to aphasia, and the employment of direct translation of the assessment tools without cultural adaptation. In addition, no studies have been found which have considered PWA in Arabic culture. Furthermore, it showed the scarcity of studies and figures in regard to stroke and aphasia in Saudi Arabia.

This review, then, has been set in a different context, other than western and Christian culture, in Saudi Arabia, where an Arabic and Muslim culture exists. The reflection of certain issues of religion and social culture in relation to the QoL for PWA was

demonstrated. This review has led to the set of research questions which will be addressed by this study.

### **1.16 Research aims**

Thus, because of the lack of research into PWA in Saudi Arabia and the field of QoL in particular in such a culture, in the light of the important differences in culture and religion, and given the specific conditions of the Saudi and Muslim context, there is a need to explore these issues in relation to QoL and its measures for this group. This literature review has generated the hypothesis of this study, which is that QoL of Saudi PWA may differ due to the differences in cultural context (Muslim and Arabic), views about health, disease and different social norms.

To this end, the aims of this study are, first, to explore the factors that affect QoL for Saudi patients with aphasia after stroke, including issues which are specific to Saudi society such as cultural and religious issues. Then, from the resulting outcomes, the second aim is to develop an assessment tool for QoL for Saudi patients with aphasia after stroke, including examining its validity and reliability, and investigating the relationships between QoL and other predictors.

# Chapter 2: The Development of the Questionnaire

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This chapter describes the approach used to develop the QoL questionnaire, the three phases of its development, and the outcome of each phase. In the first phase, the existing measures of QoL for aphasia were reviewed and the cross-cultural adaptation process was applied. The second phase investigated the views of three groups: Saudi Speech Language Pathologists (SLP) as professionals, Saudi lay people who had or knew patients with aphasia (PWA) as non-professionals, and Saudi PWA themselves. This chapter then focuses on how, by triangulating these views, the main themes for the questionnaire were produced. This led to the pilot version of the questionnaire for Saudi PWA, as the third phase of this process. The chapter finishes by describing the outcome of this pilot, and shows how it was reviewed in order to produce the final version of the questionnaire.

## 2.1 Rationale and framework for developing the questionnaire

To meet the needs of this study, there were two options: the development of a new measure, or the use of a direct translation of an existing measure. As discussed before, the translation of an existing measure might not have been appropriate due to cultural differences, so the development of a new measure was chosen. This was not an easy choice because, as Aaronson, Ahmedzai, Bergman, and Bullinger (1993) noted, the validation process for QoL measures requires a large sample size when the cultural setting is a crucial factor, such as a different country or language. Also, a great deal of effort is needed to select the themes and items which should be included, as explained earlier in the literature review chapter under the HRQoL and QoL sections.

Before starting the process of developing the questionnaire, research was conducted with people for whom the tool was intended. In this way, general ideas and issues on the QoL measure for PWA were gathered by contacting professional colleagues, Saudi PWA, and ordinary people, who were asked about which issues might have an impact on the QoL of Saudi PWA. This provided another perspective as a starting point for the process of developing the questionnaire. The preliminary work indicated that there were a limited

number of QoL measures for PWA, and none in Arabic/ Islamic culture. As QoL is clearly a multi-dimensional construct, the dimensions/ domains appropriate for Saudi PWA had to be identified. The process began with a broad review of the literature on QoL and the existing measures, and then an exploration of the views of the stakeholders involved in this project, starting with the professionals, then ordinary people and finishing with the views of the PWA. The aim was to have a clearer perspective of QoL by starting from a general perspective of QoL and ending with a more specific one for PWA. These phases in the development of the questionnaire are explained in detail in **section 2.3**.

## 2.2 Methodology

An integrated approach combining qualitative and quantitative research methodology was used in this study. This approach is encouraged by Depoy and Gitlin (2005), who argued that it “involves selecting and combining designs and methods from both traditions (quantitative and qualitative methods), so that one complements the other to benefit or contribute to an understanding of the whole” (p.28). Qualitative research can be used to support quantitative research by providing more information about the measured variables involved, and to formulate a hypothesis about their relationships. On the other hand, quantitative research obtains information more efficiently by using, for example, a questionnaire which gathers information which cannot be collected by other methods; it also enables a larger sample to be covered. These two methods can be combined, both to explore different aspects of a phenomena and to obtain participants’ perspectives simultaneously (Bryman & Teevan, 2005). This mixed method framework was used to view QoL from different perspectives (a triangulation process), to develop a better understanding of the concept of QoL. This process merges qualitative and quantitative data to compare and validate the results of the triangulation process. This method is used to gather rich data which provide an in-depth understanding of the concepts under investigation, and which also allow for some degree of generalizability of the obtained findings. Moreover, because concepts such as QoL, religious beliefs and psychosocial life values are personal issues that depend on underlying factors such as culture, age, nature of social life and previous experience (**see Chapter one**), these concepts clearly cannot be studied via quantitative research methods alone. In this way, the process was used to establish the external validity of the research (Bowling, 2002), to allow the views and opinions of key people (professionals, non-professionals and PWA) to be explored. This triangulation process for the data from these different sources increases the wider

understanding of the phenomenon under study (Shih, 1998). Also, Denzin (2009) argues that triangulation enhances the validity of the study, as do Creswell and Miller (2000), who note that triangulation can be “a validity procedure where researchers look for convergence among multiple and different sources of information to form themes or categories in a study” (p. 126).

### **2.3 Development phases**

#### ***2.3.1 Phase one: reviewing existing measures and the cross-cultural adaptation process***

##### ***2.3.1.1 Reviewing existing measures***

The main aim of the review was to identify assessments of QoL in relation to aphasia and for PWA and its impact post-stroke, and to study the advantages and disadvantages of the relevant measures as well. Measures were identified through a variety of means, clinical knowledge of existing measures, and searching databases from a variety of disciplines using appropriate and relevant search terms (Bowling, 2002) to identify any measures not already known to the researcher. Additionally, measures were reviewed which have been frequently cited in studies and other work related to the subject of the study. This review included Arabic and Islamic culture, as well as different adaptations of such measures to other languages and cultures. Moreover, the preferred mode of administration was for an interviewer-administered self-reported measure rather than a self-administered one, to overcome the communication difficulties for PWA who do not necessarily do well with written questionnaires (Worrall & Holland, 2003).

As criteria for selecting the measures, the researcher looked for measures designed for adults and self-reported scales with an interview-based administration, as well as for scales for use without proxies. The measures not only needed to have a simple scoring procedure and clear layout for patients with reading and visual problems, they also had to be quick to complete. The scales themselves were required to have certain psychometric criteria/ properties, such as good reliability (test/ retest reliability and internal consistency), good validity (content and/ construct validity), and good accuracy and accessibility. The evaluation of this review was carried out by the researcher applying knowledge of the research concepts rather than doing a systematic review or applying a critical appraisal tool.

The review elicited QoL measures in a wider context for the general population, as well as those specifically designed for PWA, and also measures of QoL in Arabic populations across different health conditions. Based on the previous criteria, some measures were found to meet these criteria while others were rejected accordingly. Thus, because of the fact that this review was general rather than systematic, and because of the need to shorten the list of measures whilst also choosing the ones most likely to meet the criteria, the researcher selected three of the most recently published and developed outcome measures commonly used clinically to measure the QoL for PWA in different domains. These selected measures were: Stroke and Aphasia Quality of Life Scale-39, (SAQoL-39) (Hilari et al., 2003), the American Speech Language Hearing Association's Quality of Communication Life Scale (QCL) (Paul, 2004) and the Communication Outcomes after Stroke Scale (COAST) (Long, Hesketh, Booth, & Bowen, 2008). These scales met the criteria that were set earlier and more objectively they have the psychometric properties to be considered good measures, such as good reliability (test/ retest reliability and internal consistency), good validity (content and/ construct validity), and good accuracy and accessibility, as shown in **Table 2.1**.

Table 2-1 The psychometric properties of the three measures

Scale	Good acceptability	Internal consistency	Test/ retest reliability	Content & construct validity
SAQoL-39	✓	✓	✓	✓
QCL	✓	✓	✓	Not reported
COAST	✓	✓	Not reported	✓

These measures are aphasia friendly measures which use simple language, short sentences, and large font questions. The SAQoL-39 covers four main areas: physical, communication, psychological and energy domains, in 39 questions presented with a 5-point Likert scale. According to Hilari et al. (2003), these domains are the most affected by stroke and aphasia. The second measure, the QCL, is designed to assess how personal relationships, social life (such as in work, leisure and education) and the well-being of the PWA are affected through three domains of measurements: socialisation/ activities, confidence/ self-concept, and roles and responsibilities. These are assessed by 17 items,

also using a 5-point Likert scale (Arpita, 2009; Paul, 2004). Both measures included individuals with different severity levels of aphasia during their development, and different domains of QoL (Cranfill & Wright, 2010). The third scale, the COAST, focuses on the role of communication and language abilities in QoL measurement. According to Cruice, Worrall, Hickson, and Murison (2003), the inclusion of a sensitive measure of communication is vital, and indeed the COAST is used to evaluate self-perceived communication effectiveness whilst also covering interactive communication, an overview of communication, and QoL and its impact from the point of view of the patients themselves. This is implemented through 20 items with a 5-point Likert scale (Long et al., 2008).

The physical activities, communication, responsibilities, social activities and feelings domains of these three measures were explored in order to reflect on the potential domains for the intended scale. There were some criteria for the selection of the questions. For each measure, the questions under each domain were selected when the question was relevant to the domain chosen and when it was appropriate to Saudi culture. They were also chosen when the questions were simple enough to be understood by the PWA, were a good reflection of the target domain, and had easily measurable responses. In addition, there were a variety of reasons for selecting these questions and not selecting others, such as because they were repeatedly found in more than one measure, for example questions regarding physical difficulties and communication. Conversely, questions were avoided when there was overlap or they were culturally inappropriate. Others were not selected because they were too specific to stroke and not aphasia, or were designed to be used by the carrier not by the patients themselves, or to avoid redundancy. After these criteria had been applied for each measure, the selected questions were merged in one report and revisited to eliminate any duplication between them.

Therefore, from the SAQoL-39, eight questions from the physical domain were chosen (SC4, SC5, M4, M6, M9, UE1, UE4 and UE5), and three from the communication domain (L3, L5 and L6). From the QCL measure, three questions were chosen (6, 8 and 15) to reflect social relationships and involvement with the social activity. From the COAST, three questions were chosen (5, 7 and 8) to reflect PWA communication problems.

For the purposes of this study, two other domains were included to explore and emphasise social culture and religious differences: religious activities, and family relationships. Both

of these were mentioned in the WHOQoL measure as social relationships and spiritual/religious/personal beliefs (WHOQoL Group, 1997). At this stage, there were seven potential domains to be explored:

- 1) The physical activities domain, involving items that deal with body movements, mobility, gross and fine motor skills, and other activities;
- 2) The communication domain, investigating the impact of speech and language difficulties on the patient's social and family life;
- 3) The responsibilities domain, exploring the change in the patient's responsibility for themselves and for others;
- 4) The social activities domain, investigating the patient's relationships with others at different levels, such as work, as well as their social contacts and support availability, and how they spend their spare time;
- 5) The feelings domain, examining the patient's feelings toward the aphasia problem, in combination with the people in their immediate surroundings;
- 6) The religious activities domain, consisting of items concerned with their main religious and worship duties, and how the patient dealt with them after the stroke and aphasia incident;
- 7) The domain of family relationships, investigating the patients' relationships with their families and support availability.

It should be noted that some minor modifications were made in the opening statements for the selected questions to help the participant's response be more focused and truthful. These included considerations of the scoring scale used, the patients' evaluation not the proxy, changing the context of the questions where the patient will be asked these questions in interview mode, and rephrasing these questions or changing the wording, whilst retaining the same idea. For more details see **Appendix A**.

The questions for religious activities and social life domains were formed based on the literature review of the religious and social life of Saudi culture. As a result, the selected questions for all domains were included as the early provisional draft of the questions list.

### ***2.3.1.2 Cross-cultural adaptation process***

The next step was to complete the cross-cultural adaptation process by adjusting the content of the questionnaire so that it reflected the social culture and religious structure

of Saudi society, and overcame linguistic and dialect differences. The literature which addresses the process of cross-cultural adaptation is varied. In this study, two combined approaches were used for the cultural adaptation process: the Mapi institution approach (Acquadro, Conway, Hareendran, & Aaronson, 2008) and the guidelines proposed by Beaton, Bombardier, Guillemin, and Ferraz (2000). The first stage of this process was to define the concepts involved in the questionnaire, using four qualified Saudi translators studying PhDs in linguistics at a UK university. They were all native Arabic speakers and proficient in English. Two translators were provided with the items involved in the questionnaire and given explanations of all the concepts behind them, while the other two translators were not given any explanations about the purpose of the study or the measure. This was done to avoid any bias and to explore new meanings or interpretations which might be found. The purpose of this process was to produce one translation based on both an academic (the first pair) and lay perspective (the latter pair).

The next stages were as follows. First, there was the forward translation (from English to Arabic) of the list of the potential questions selected. These questions were separately translated by the two groups of linguistic experts. Each individual translation was accompanied by a written summary report containing feedback about the difficulties they had faced, their choices and their remarks. The translators were chosen to represent the different parts of Saudi Arabia (northern, southern, eastern and western provinces) and the terminologies and vocabularies that are commonly used in each area. The next stage was to synthesise the translations, with all the translators working together to produce one agreed common translation in Arabic. After this step, the synthesised Arabic version was translated back into English by the two qualified translators, who had no previous knowledge of the aim of this scale.

The final stage was the group/committee review, which involved all those participating in the translation process and the researcher. They reviewed these items/questions in order to make them as appropriate as possible for Saudi PWA. The decisions made were based on the guidelines and approach for cross-cultural adaptation by Beaton et al. (2000), and Guillemin, Bombardier, and Beaton (1993). This involves achieving equivalence in the following areas: semantic equivalence, i.e. words having the same or multiple meanings, or grammatical difficulties; experiential equivalence, i.e. items are chosen to capture experience of daily life so a given item may simply not be experienced in the target culture, for example the use of a fork when eating is not common in Saudi Arabia; conceptual

equivalence, i.e. words may have different meanings between two cultures or two areas, for example the concept of family is different for the nuclear and extended family. This committee reviewed all the questions in Arabic and English, refined them and developed a final provisional draft of the questionnaire to be used in the next phase.

### **2.3.2 Phase two: the triangulation process**

#### **2.3.2.1 Professionals' views (Saudi speech language pathologists)**

As part of the triangulation process, this provisional draft of the questions was sent via email to Saudi speech language pathologists (SLP) in Saudi Arabia registered at the Saudi Society for Speech Language Pathology and Audiology (SS-SLPA). This was done in order to explore their views as professionals about the QoL for Saudi PWA and the impact of aphasia on their QoL and therapy programmes, according to their experience with these patients. The professionals participating in the study had to have at least one year of clinical experience with aphasia and Saudi PWA. The survey was sent as an online questionnaire through the website Survey Monkey. It was in English and contained 42 questions distributed across the seven areas, so that each question in each domain started with a statement (e.g. 'in your opinion', 'according to your experience with PWA,' 'how important is it to the patient to ... e.g. speak with others?'). There was also a 5-point Likert scale as follows 1 –not important at all, 2 –not important, 3 –neutral, 4 –important and 5 –very important. There was also an 'other' option (to specify) and for comments and feedback.

They were encouraged to add any themes or sub-themes they thought were important and to rank them accordingly. The questionnaire started with a brief about its purpose, and how the respondent could leave their input/remarks and suggestions. They were asked to make suggestions on the questions and items, and the themes involved, such as additions, deletions and rephrasing, that might help and serve the purpose of the intended questionnaire, whether in regard to the structure, language or layout.

The professionals were given two weeks to respond and nine out of 17 speech language pathologists working with aphasia, out of 123 SLP registered in SS-SLPA, completed the questionnaire successfully. Each answer was given a weight as follows: 1 for not important at all, 2 for not important, 3 for neutral, 4 for important and 5 for very important. For each question, the response percentage for each answer was multiplied by its weight and then these were added; the result determined how important this question was and

whether it would be excluded in the questionnaire), see **Appendix B**. The criterion for excluding the question was where the weight of the question was less than three (the average).

According to this criterion, the questions that were important in the view of the professionals were gathered and then categorised into the themes and sub-themes that they represented. In regard to the added items, questions and themes/sub-themes that were indicated and suggested as either important or very important by more than half of the participants were represented. These included depression post-aphasia and the impact of the patient's improvement in the rehabilitation programmes. The results are shown in **Table 2.2**.

Table 2-2 Themes and sub-themes resulting from the professionals' views

Themes	Sub-themes
1-Physical difficulties	Daily life activities at home Depending on others Self-caring (self-cleaning)
2-Speech difficulties	Speech difficulties Communicating with others Memory problem
3-Social changes	Their role change in the family Family and friends support Social involvement
4-Psychological changes	Self confidence Loss of respect and importance in the society Depression ( <b>added</b> ) Others' feelings toward them (sorrow & pity)
5-Religious involvements	Doing the prayers like before in the Masjid Remembering/recalling the Quran Doing ablution
6-Rehabilitation impact ( <b>added</b> )	Improvement in their rehabilitation programme ( <b>added</b> )

### 2.3.2.2 Ordinary Saudi people's views

In addition to considering the professional perspective, it is important to gather information from individuals within Saudi society, in order to reflect the culture and recognize the views of the PWA's family members and carers. The use of the term "ordinary" is used here to differentiate them from other people with aphasia (PWA).

However, it is difficult to have direct contact with them face to face to ask them about their relatives or persons they know to have aphasia, due to cultural customs of speaking about such a disease in public, as mentioned earlier. This is in addition to the difficulty of accessing people within the premises where the patients (their relatives) are found. For such reasons, it was suggested to use the internet within a recognized forum to reach as many as people as possible and make the information more accessible and convenient for people to disclose their opinions. To this end, an open-ended question survey was sent via email to a recognized online forum of the Saudi nationals' abroad website (<http://www.mbt3th.us/vb/forum.php>). Registration in this forum is not exclusively restricted to students, but the forum itself required its members to be adult (over 18 years of age) and Saudi nationals, with no other restrictions. It was expected that almost 500 people might receive the questionnaire, and there was only one condition for participation: the participant had to have a family member who had experienced, or was experiencing, aphasia or to know someone, such as a close relative or friend. Participants were given a link to the questionnaire on the Survey Monkey website, where they were provided with an explanation of the purpose of the study and the survey, and instructions on how to respond to the questions. It was emphasised that aspects or themes were only mentioned as examples of what the researcher expected, and they were not restricted in their responses. This survey was structured differently from that given to the professionals in order to give the participants the opportunity to express their views in an easier and informal way, because the researcher had no knowledge about the participant's background or education level. For this reason, the survey was designed to suit the ordinary/ layperson participant. The survey was in Arabic and the questions began with the statement, "In your opinion what is/ are the aspect/s (thing/s) of life that you consider to be important to the patient with aphasia? Then, could you please order/rate/rank them according to their importance in their life, where 1 is for the most important and 5 for the least? You will be provided with examples of some aspects that we think but these may not be true for these patients. For example: In your opinion, if you think physical disability is important, what is/ are most important physical activities in the daily life of the patient with aphasia? For example, is it taking a shower, preparing his/ her food, driving a car, walking, doing sport...etc.? You can order them, for example, from 1-5, where 1 is the most important and 5 is the least." This was followed by a space so they could write down their responses and views. The aspects which were indicated to the participants and the given examples in this survey were the same as those presented in the previous survey for

SLPs. These non-professional participants were treated differently from the SLPs who were familiar with doing such a survey in a scientific way. The examples were presented to help the participants know what was meant by general or certain aspects of life for the PWA, especially when those participants did not have full knowledge of the condition in all its aspects, or only had a superficial knowledge of aphasia as a disorder. Another reason for the different treatment was to give these people the opportunity to elaborate on and expose any other aspects of the measure which may have been omitted. Furthermore, it is not known how far the concept of QoL is known among Saudis in general. The participants were asked to add any other themes or items they thought should be added as an important item, and to rank them; in addition, they were encouraged to give suggestions and comments in regard to the questions themselves and to the study as a whole. Thus, these participants were given the chance to develop new themes and were not restricted either to potential themes through example questions, or to the order in which the themes appeared. After the deadline, 66 of the 92 people who opened the survey link had responded. As mentioned earlier, it is not a condition for the registration and membership for those people in this forum to live outside Saudi, but when collecting the responses and by checking the location of these members, it appears that 48 out of the 66 members who participated were in Saudi Arabia. This supports the use of such a forum. In addition, 23 of these participants had people with aphasia, while others knew someone such as a close relative or a friend who had experienced aphasia. Of these, there were 23 females and 43 males aged between 18-64 years, with an average age of 37. Other characteristics were not available to the researcher.

In this phase and the next stages of the triangulation process, thematic analysis procedure for the data was used to review the data obtained by recording the responses and statements for each participant. Then, the researcher created broad categories using the potential domains as headings/themes of the categories, and these headings were abbreviated to be both meaningful and easily recognizable by using colours and initials to represent each category (coding). Under each category, sub-headings/sub themes were listed for further categorisation. During this process, important themes were identified, through reading/re-reading of the responses, to confirm understanding of the discussion when looking for emerging themes as they related to potential domains. After completing this task, some items were grouped under potential themes and others under sub-themes. Here, the responses for each participant were collected separately, and then these responses were reviewed by applying the thematic analysis, and similar clear themes from

the responses were grouped under the general theme, while unclear ones were put aside for further review.

For the theme to be included and confirmed as a potential theme/ domain in this phase, the theme had to have been mentioned by 25% or more of the total participants, in order to include most themes suggested by the respondents as representative for their views. As the identified themes reproduced ideas with a similar meaning, the resulting themes were arranged into units as defined by Taylor and Bogdan (1989) as “conversation topics, vocabulary, recurring activities, meanings, feelings, or folk sayings and proverbs” (p.131). In addition, theme identification was completed by “bringing together components or fragments of ideas or experiences, which often are meaningless when viewed alone” (Leininger, 1985, p. 60). Themes also came to light when the respondent’s pieces of information were collected to form the whole picture of their experience. These themes were then classified into specific and related domains, as shown in **Table 2.3**.

Table 2-3 Themes and sub-themes resulting from non-professional, ordinary Saudi people

Themes	Sub-themes	Status
1-Physical difficulties	Daily life activities at home Self-caring (self-cleaning) Driving the car alone Walking independently	Existed Existed Added Added
2-Speech difficulties	Communicating with others Memory problem Expressing their immediate needs	Existed Existed Added
3-Social changes	Their role change in the family Family and friends support Social involvement Others’ acceptance Feeling isolated from society Outdoor activities Continuation of their relationships with others after the incident No social clubs available for these cases	Existed Existed Existed Existed Added Added Added Added
4-Psychological changes	Loss of respect and importance in society Depression Feeling useless Others’ feelings toward them (sorrow and pity) Mood change	Existed Existed Existed Existed Added
5-Religious involvements	Doing the prayers like before in the Masjid Remembering/recalling the Quran Doing ablution Therapy/healing by reading the holy Quran	Existed Existed Existed Added Added
6-Care giver involvement (Added)	The impact of this problem on care givers The relation with the spouse Dependence on house mates or drivers, such as for cooking	Added Added Added

Themes	Sub-themes	Status
Rehabilitation impact ( <b>dropped</b> )	Improvement in their rehabilitation programme	Dropped
Existed: emerged previously from the professionals views. Added: mentioned by the ordinary people. Dropped: not mentioned by the ordinary people.		

At this stage, the lists of themes and sub-themes which emerged from both the professionals SLPs and non-professional ordinary Saudi people were collected and reviewed using thematic analysis. Similarities and differences were found and a common list was produced. The end result is shown in **Table 2.4** below, which represents the resulting themes and sub-themes and also shows those which were redistributed after the thematic analysis review.

Table 2-4 The themes and sub-themes which emerged from the professional and non-professional views

	Themes	Sub-themes		Themes	Sub-themes		Themes	Sub-themes
Saudi Speech Language Pathologists	1-Physical difficulties	Daily life activities at home Depending on others Self-caring (self-cleaning)	Non-professional Saudi ordinary people	1-Physical difficulties	Daily life activities at home Self-caring (self-cleaning) Driving the car alone Walking independently	Combined views of the Saudi Speech language Pathologists and Non-professional Saudi ordinary people	1-Physical difficulties	Daily life activities at home Depending on others Self-caring (self-cleaning) Travelling alone by car Walking independently
	2-Speech difficulties	Speech difficulties Communicating with others Memory problem		2-Speech difficulties	Communicating with others Expressing their immediate needs Memory problems		2-Speech difficulties	Speech difficulties Communicating with others Expressing their immediate needs Memory problems
	3-Social changes	Their role change in the family Family and friends support Social involvement		3-Social changes	Their role change in the family Family and friends support Social involvement Feeling isolated from society Outdoor activities Others' acceptance Continuous of their relationships with others after the incident No social clubs available for these cases		3-Social changes	Their role change in the family Family and friends support Social involvement Isolation from society Outdoor activities Others' acceptance Continuation of their relationships with others
	4-Psychological changes	Self confidence Loss of respect and importance in the society Depression Others' feelings toward them (sorrow and pity)		4-Psychological changes	Loss of respect and importance in the society Depression Feeling useless Mood change Others' feelings toward them (sorrow and pity)		4-Psychological changes	Self confidence Loss of respect and importance in the society Depression Uselessness Mood change Expressing their feelings Others' feelings toward them (sorrow and pity)

	Themes	Sub-themes		Themes	Sub-themes		Themes	Sub-themes
	5-Religious involvements	Doing the prayers like before in the Masjid Remembering/recalling the Quran Doing ablution		5-Religious involvements	Doing the prayers like before in the Masjid Remembering/recalling the Quran Doing ablution Therapy/healing by reading the holy Quran		5-Religious involvements	Doing the prayers like before in the Masjid Remembering/recalling the Quran Reading & understanding the Quran Doing ablution Therapy/healing by reading the holy Quran
	6-Rehabilitation impact	Improvement in their rehabilitation programme		6-Care giver involvement	The impact of this problem on the care givers Relations with the spouse Dependence on house mates or drivers, such as for cooking		6-Rehabilitation impact	Improvement in their rehabilitation programme No social clubs for these cases  (This whole theme was added)
							7-Care giver involvement	The impact of this problem on the care givers Relations with the spouse Dependence on house mates or drivers

**Table 2.4** shows that common themes emerged from the two groups, but also that some themes were presented only by the non-professionals, such as care giver involvement, therapy/healing by reading the holy Quran and driving the car alone. Similarly, only the professional group presented the rehabilitation impact theme. At this stage, the resulting themes and sub-themes from both groups were compared and filtered in order to determine which overlapping themes should be excluded. It was found that the rehabilitation impact resulted as a new theme, including new sub-themes to be added.

In this way, seven themes were identified with 31 sub-themes. Other suggestions from the SLPs on the layout and the format, such as having a larger font size and using colours, were also considered as this questionnaire was to be used with PWA in clinical settings. As a result, a new draft of questions was developed as a first version (**VR1**), which was designed to be aphasia friendly and communicatively accessible to all PWA, including those with severe aphasia. These factors were taken into account by the researcher and applied later in the pilot and main study, by using large font and short, simple sentences for the questions, which were presented on white paper.

**VR1** was again sent using the same method of ranking as before to the same nine Saudi SPLs. According to Fayers and Machin (2007), assessing the item relevance and whether the items involved are appropriate to the construct under investigation is commonly approached by using an expert panel and the opinions of patients themselves (which was done at a later stage). In addition, in practice it is experts such as these who will use the questionnaire in a clinical setting and so their views on its application need to be considered. Also, this new drafted questionnaire was sent to the same ordinary Saudi people to rank the questions on this new draft questionnaire. This was done according to their importance to patients from their point of view, from 1-5, where 1 is the most important and 5 is the least. The second set of responses from both groups was collected.

Eight out of nine participants from the professional group and 50/66 participants from the ordinary people fully responded. These responses from the 58 participants for each question were collected and evaluated using the same procedure as previously used, where the response percentage for each answer was multiplied by its weight as follows: 1 for not important at all, 2 for not important, 3 for neutral, 4 for important and 5 for very important, and then these were added; the result determined how important this question was and whether it would be excluded

in the questionnaire using the same criterion of having three or more on the responses before being included.

As a result of this review, one entire theme on rehabilitation impact was deleted because all its questions were less than the average; for the same reason, some sub-themes were deleted from their main themes, such as depression and mood changes from the psychological changes theme, the sub-theme of healing and therapy by reading the holy Quran from the religious involvements theme, and the sub-themes of the impact of this problem on care givers, and dependency on house mates or drivers and relationship with the spouse from the care giver involvement theme. There are some insights into why some items were deleted from the professionals' perspective. For example, the exclusion of healing and therapy by reading the Holy Quran may have been because this type of therapy or healing is not limited or exclusively used only when the person is ill. Rather, listening to the Holy Quran or even being engaged in prayers is recommended even for healthy people to have the feeling of peace, and encourage their trust in God, and so it is for all. Also, it might have been because most of the patients had tried this kind of therapy or treatment before; during medical treatment, it is recommended in the Islamic instructions to do Ruqyah (reading verses from the Quran) when the person does not feel well and when there is no conflict with the medications given or in case the cure is not known, and so it is done by everyone. Depression and mood changes were not considered here, perhaps because professionals feel that depression and mood changes could happen to the patients at the beginning of the problem and the shock of the incidence, and when they suddenly depend totally on others on their DLA, but not when they become used to it as a chronic illness and start coping with the difficulties. This does not exclude the patient's religious beliefs of acceptance of God's fate to cope with the distress after the stroke. However, for dependency on others (care givers, housemaids, drivers and spouse), was not considered important; this may be because domestic helpers are common in Saudi houses, as Saudi people depend on them in many activities even when healthy and it is not a *change* for a patient to depend on them. Even with the spouse, duties and responsibilities inside the house and for the patient in particular can be taken on by housemaids or drivers.

The researcher changed some theme names to reflect and represent the underlying sub-themes and questions. For example, the physical difficulties theme changed to physical and daily life activities, while speech difficulties became communication, social changes became social and family relationships. Psychological changes became the feelings and emotions theme, and

rehabilitation impacts given the name interests and leisure theme. Finally, the religious involvement theme changed to the religious duties and activities theme. These new themes and sub-themes can be seen in **Table 2.5**. Accordingly, they were used to construct the second version of the drafted questionnaire (**VR2**) with six themes and 25 sub-themes.

Table 2-5 The new themes and sub-themes in the second version of the questionnaire (VR2)

	Themes	Sub-themes		New themes	New sub-themes
Version 1 of the questionnaire (VR1) with the suggested changes	1-Physical difficulties → <u>Changed</u> to Physical and daily life activities	1-Daily life activities at home 2-Depending on others such as house mates and drivers 3-Self caring (self-cleaning) 4-Travelling alone by car 5-Walking independently	Version 2 of the questionnaire (VR2)	1-Physical and daily life activities	1-Daily life activities at home 2-Depending on others 3-Self caring (self-cleaning) 4-Travelling alone by car 5-Walking independently
	2-Speech difficulties → <u>Changed</u> to Communication	1-Speech difficulties i.e. conversation/ phone 2-Communicating with others 3- Expressing their immediate needs 4-Memory problem		2-Communication	1-Speech difficulties 2-Communicating with others 3- Expressing their immediate needs 4-Memory problem
	3-Social changes → <u>Changed</u> to Social and family relationships	1-Their role change in the family 2-Family, friends and colleagues support 3-Social involvement		3-Social and family relationships	1-Their role change in the family 2-Family, friends and colleagues support 3-Social involvement
	4-Psychological changes → <u>Changed</u> to Feelings and emotions	1-Self confidence 2- Loss of respect and importance in the society 3-Depression ( <b>Deleted</b> ) 4-Uselessness 5- Mode change ( <b>Deleted</b> ) 6-Expressing their feelings 7-Others feelings toward them (sorrow and pity) 8-Others' acceptance 9- Continuity of their relationships with others, such as at work		4-Feelings and emotions	1-Self confidence 2- Loss of respect and importance in the society 3-Uselessness 4-Expressing their feelings 5-Others feelings toward them (sorrow and pity) 6-Others' acceptance. 7- Continuity of their relationships with others
	5-Religious involvements → <u>Changed</u> to Religious duties and activities	1-Doing the prayers like before in the Masjid 2-Remembering/ recalling the Quran 3- Reading & understanding the Quran 4- Doing ablution 5- Therapy/Healing by reading the holy Quran → ( <b>Deleted</b> )		5-Religious activities and duties	1-Doing the prayers like before in the Masjid 2-Remembering/ recalling the Quran 3-Reading & understanding the Quran 4- Doing ablution
	6-Rehabilitation impact → <u>Changed</u> to Interests and leisure	1-Improvement in their rehabilitation programme ( <b>Deleted</b> ) 2- Social clubs for these cases 3-Isolation from society 4-Outdoors activities		6-Interests and leisure	1- Social clubs for these cases 2-Isolation from society 3-Outdoor activities
	7-Care giver involvement ( <b>Deleted</b> )	1-The impact of this problem on the care givers ( <b>Deleted</b> ) 2-The relation with the spouse ( <b>Deleted</b> ) 3-Dependency on house mates or drivers ( <b>Deleted</b> )			

### 2.3.2.3 Views of Saudi PWA

In order to increase both the face and content validity of the measure, the views of PWA were investigated. The triangulation process was completed at this stage, considering the views of

the patients themselves in addition to the views of professionals and non-professionals investigated earlier. According to Marquis and Jackson (2000), in order to gain insight into QoL experiences for people with disabilities, it is important to gather information from those with disabilities and recognise the experiential nature of QoL, so that individual preferences can be valued and supported. The views of patients were investigated by using semi-structured interviews and by applying **VR2** of the questionnaire.

### **2.3.2.3.1** *Semi-structured interviews*

The purpose of the semi-structured interview was to evaluate whether most of the themes on QoL were covered in the measure, and to decide if any items should be added or deleted according to the views of the PWA. The semi-structured interview used an approach similar to that adopted by Le Dorze and Brassard (1995), where “themes and some focused questions were formulated before subjects were interviewed in order to ensure that several areas of interest were covered” (p.242). According to Dornyei (2007), the semi-structured interview is appropriate when the researcher has a sufficient overview of the phenomenon and is able to develop broad questions about the topic in advance, but does not require readymade response categories that would limit the depth and size of the respondent’s story. On this basis, the semi-structured interview was chosen because the aim was to explore a specific topic during the interview, QoL. Here, a sub-set of topics was listed to help the researcher concentrate on these issues. In addition, the purpose of this interview was not to test the patients, but to facilitate the expression of their opinions on QoL, especially in connection with aphasia. The questions used were open-ended, prompted and flexible, allowing new questions to be raised during the interview according to responses and in so doing best serve the purpose of the study. Another reason why semi-structured interviews were seen as the most appropriate method of collecting data was that they allow for a degree of consistency of approach whilst also allowing for explorations of particular issues of importance to respondents (Atkin, Twigg, & Perring 1990).

### 2.3.2.3.2 Interview guide

The semi-structured interview was designed around certain key questions that had been composed and written in advance. In addition, the researcher (interviewer) prepared himself for unclear ideas or opinions that might be raised by the participants, and so probing questions were prepared. It was important for the researcher to have a written interview guide in order to be systematic and consistent in the interview. According to Grbich (1999), open-ended questions asked of all participants should have the same sequence and use the same interview procedure, so that all the questions are consistent in their order and structure. This reduces the level of influence of the interactions and builds a rapport between the interviewer and the interviewee which can improve the quality of the data. An interview guide was also developed which drew on similar PWA studies. The questions used in this stage were adapted from (Cruice et al., 2010, p. 332), keeping in consideration the different cultural setting in which the study was conducted. These questions were reviewed in order to serve the purpose of the interview here, as Cruice's study employed questions which were unprompted and asked in a structured interview method, rather than an in-depth interview. In Cruice's study, these questions were used in a similar way as in Fraquhar's study (1995, p. 1442), when investigating elderly people's definitions of QoL.

The questions used in these two studies were as follows:

- 1- How would you describe the quality of your life? And why do you say that?
- 2- What things give your life quality?
- 3- What things take quality away from your life?
- 4- What would make the quality of your life better?
- 5- What would make the quality of your life worse?
- 6- Does communication have an impact on the quality of your life? If yes, then how?

Only the sixth question was added to the original questions by Cruice et al. (2010) to suit this study. These questions were both voiced and presented individually in a written format to each patient, but questions two and three were rephrased for some participants to make them easier to understand. The responses were not timed or probed by the interviewer.

In this study, similar questions were used, but they were changed because the term QoL is not popular or commonly used by the Saudi population. Thus, in order to suit Saudi PWA, their

culture, their knowledge of the QoL concept and the purpose of the study, changes were made as follows:

1-What makes your life good? Does anything else make it good?

2-What makes your life bad? Does anything else make it bad?

3-What things would make your life better? Would anything else make it better?

4-What things would make your life worse? Would anything else make it worse?

5-Are there other things you would like to do which are difficult for you? If yes, this question was followed by: What makes it difficult?

6-What are your wishes to enjoy better QoL?

7-Are you familiar with the term 'quality of life'? If yes, what does it mean to you? How?

If no, this was explained in relation to life satisfaction such as to have good health, good work or to enjoy life.

8-Is there anything else you would like to add?

The modified questions have the same purpose but were asked in a different way. The opening statement of each question used was put in simple words and language, to be clear and easily understood. The researcher supported the participants in their understanding by asking the questions in different ways and using different props. When clarification of a patient's response was required, the interviewer asked for an explanation. There was no time limit for the participant's responses to the questions.

To ensure the comprehension of the questions by the participants, the open-ended questions were presented to each participant in written format and read aloud. Also, some of the questions were rephrased for patients who had difficulty understanding them or who needed more clarification of the terms used in the questions, such as "difficult."

The process of questioning during the interviews was similar to the funnelling approach used in qualitative interviews, as described by Minichiello, Aroni, Timewell, and Alexander (1995).

In effect this introduces a broader topic and then narrows it down towards specific areas of interest through further questions. In this way, the interview began with general questions about whether the aphasia after stroke had changed certain aspects of their lives, and if so, how, and when it was good or bad. The questions then became more specific, so that the process was easier and clearer for them. Then, the concept of QoL was introduced to each participant, who was also asked about their familiarity with the term and what it meant to them. If the participant had no familiarity with the concept, the term QoL was rephrased in more familiar terms, in relation to their perception of satisfaction with life as a whole. It was important that the process was gradual to ensure that all the themes covered in the questionnaire were addressed.

From the interview guide, it can be noticed that the first two questions targeted the patients' views of their current status of life. The third and fourth questions explored the future status of life after the aphasia occurred, in order to have their reflections on the effect of aphasia after stroke, on their life, and what they most wanted for good QoL. Therefore, present and future time was included in the QoL topic for these questions. The patient's optimum goals or their dreams for a good life were also considered.

#### 2.3.2.3.3 *Ethical Considerations:*

- a) ***Ethical approval:*** Initially, ethical approval was obtained from the Faculty Ethics Committee at Newcastle University. Based on this, permission was sought from the sites and departments where the study took place prior to commencing recruitment of subjects. Therefore, another ethics application to conduct this study was submitted to the participating institutions and the ethical approval was granted by their Ethics Committees. Documents relevant to ethical approval are presented in **Appendix C**.
- b) ***Informed consent:*** All participants were provided with written information sheets about the study and individuals were allowed to take information sheets away to discuss with relatives or spouses prior to consent forms being given, allowing time to consider whether or not to participate, and signed consent forms were collected prior to participation.
- c) ***Participants' rights:*** Participants were informed that they were under no obligation to participate, and could withdraw from the study at any time without giving reasons, and without affecting their status as patients at the site. They were also notified of their right to have copies of the results of this study when completed.

- d) **Confidentiality:** Participants were identified by a code number. Names and other identification details were not used in the data. All participant records and information were kept safe. Participants were assured that any quotations from interviews would be kept anonymous.

The use and publication of the research results, the storage of data and benefits of research were explained verbally and in writing to the potential participants. It should be noted that appropriate consent was gathered from participants at all stages of the study.

#### **2.3.2.3.4 Participants in the semi-structured interview**

The participants were recruited from two different sites located in the capital, Riyadh, where speech therapy services are provided to Saudi patients of all different backgrounds from across the country. The first site is a government hospital and the other is a non-governmental, non-profit hospital. The targeted population was characterized as follows (selection and inclusion criteria): Saudi adult PWA due to stroke of at least three months; adequate cognitive and mental abilities with no co-morbidity conditions, and living at home before the onset of aphasia. There were no restrictions on severity, gender, marital status, social and economic status, educational level and employment status. This information was obtained from the patients' medical notes and confirmed through a short interview with the participants.

To identify the eligible participants in the participating sites, a review of the records of the SLP clinic was used, and this was accomplished by the SLP in charge of the department, along with the researcher. Data were collected on age, sex, marital status, economic status, education, diagnostic stroke, co-morbid conditions, functional status, motor impairment, and depression, if any. Once appropriate subjects were identified for inclusion in the study and they had verbally agreed to meet, they were provided with printed materials containing information about the study and their expected participation. Eleven patients (three females and eight males) agreed to participate. Questions about the study were dealt with at this point and participants were given a written consent form to sign to assure them of their confidentiality and rights.

Both the interview and the questionnaire, which was done later, took place in a quiet room and was audio recorded. The audio-digital recordings for each patient were collected and reviewed for the identification of patterns of experience. It should be noted that one site video recorded some of the patients for their own routine clinical records, by agreement and without interfering

with this study, while the other site did not. The length of the interviews ranged from 45-90 minutes.

Using care givers or healthcare providers as proxies or as other sources of information is problematic and requires caution as there is significant evidence to suggest that proxies create bias within a study (Cruice et al., 2005). As a result of the strong reservations from the professionals in the field of QoL against the use of proxies, they were not used in this study.

Thus, first the researcher met with the patient alone. The SLP could attend the session in the room with a copy of the open-ended questions, both as an observer and also to help, in severe cases only, in explaining the questions to the patient or their responses to the researcher, according to his/her knowledge of the patient's communication difficulties. The SLP could write the responses of the patients for each question as he could interpret it instantly (**see Appendix D**).

If a family member/ care giver or healthcare provider was present, this person was politely asked, before the session started, not to participate in any way.

#### ***2.3.2.4 The outcome of the interviews***

##### ***2.3.2.4.1 Analysis of the interviews and the findings***

The main objective of the interviews was to generate a common list of themes that are relevant to aphasia after stroke for Saudi PWA. Most qualitative researchers maintain transcriptions for interview analysis. Although transcribing seems to be a straight forward technical task, in fact it involves judgements about what counts as data for a particular study, the level of detail required (verbal and non-verbal), how things are captured and said, what contextual detail is necessary to interpret data and how that data should be represented. In addition, the process requires reduction, interpretation and representation of this audible interview into a readable and meaningful written text (Bailey, 2008).

In this study, the researcher is not interested in the linguistic structure or the syntax details of the participants' answers. In order to serve this objective, the interviews were analysed by taking notes from the audiotaped recording instead and then thematic analysis was applied. This decision was made to confirm the reliability and validity of the data obtained. However, other factors played a part, such as the time, costs, unavailability of the software applicability

to Arabic language and expertise needed for the full transcription of the data collected (data transcribers and proof readers, and the training of data managers).

In this study, the researcher used a similar approach to that used by Wilkinson (2004), the thematic content analysis approach, which involves the coding of similar segments of text which are identified within the data and not from pre-existing categories, and then counting the frequencies of these codes. These codes are identified from careful reading of the text while the frequency of the codes involves the interpretation of the direct visible components and underlying meaning of the text, as indicated by Graneheim & Lundman (2004).

The review for each recording was done independently by both the researcher and the SLP at the site. Therefore, copies of the recordings were given to the site SLP, who was asked to listen to the recording for each patient and make notes on the responses to the questions of any means of communication either verbal, non-verbal, gestures or signs, when videos were available, and to give their interpretation of what the patient meant. The researcher also followed the same process. It was predicted that the patients' patterns of experience would be identified from direct quotations or from paraphrasing common ideas espoused by the patients themselves. This information was then cross-checked with what had previously been written during the interview session to confirm it. In this way, by the end of the interviews, written notes as text on all 11 patients had been collected by both the researcher and SLP, and this was done independently for each recording. The researcher and the SLP met to compare the similarities and differences found in the text notes, and to discuss these to achieve a common report. The responses for each patient were collected in a similar way to that used previously when collecting the views of the Saudi ordinary people through the survey. The researcher and the SLP highlighted the most frequently repeated component (statement) in response to each question by all participants, where each colour represented a code for different aspects.

Therefore, based on the patient's responses, and taking time to listen again when necessary to the recordings, these statements were coded and classified according to their common nature and features. Then these codes were counted for inclusion and categorization into themes where the criteria were applied.

Where video was available, the researcher and the SLP rechecked the patients' signs or gestures (non-verbal communication) when this was needed. This led to the production of a report of

commonly recognized themes and concepts, and this common report for each patient was used as the source for thematic analysis.

This analysis was performed for each interview question from both reviewers' reports (the researcher and the SLP) and from the common report for each patient. The next step was to identify all data linked to the related patterns to be classified into sub-themes. This accords with the notion that thematic analysis collects similar themes together in groups, or places like with like, in order to comprehend a phenomenon (Riley & Hawe, 2005). This study considered themes in the same way as Taylor & Bogdan (1984), who state that thematic units are derived from patterns, such as "conversation topics, vocabulary, recurring activities, meanings, feelings, or folk sayings and proverbs."

In this part of the study, the thematic analysis was performed without trying to fit this process into the researcher's analytic preconceptions or pre-existing coding frame. In this sense, this form of thematic analysis is data-driven and inductive. Within this approach, the recordings were listened to and the notes that were taken were read and re-read to detect any theme related to QoL, without paying attention to the themes that the researcher might have identified earlier, as this might have biased the results. However, it has to be acknowledged that simply having prior knowledge of the potential themes could indeed lead to a degree of potential bias.

Examples of the participants' different responses and the interpretation by the researcher and SLP for the open-ended questions are provided in **Appendix E**. An example of a communication unit is illustrated below in Figure 2.1, where the communication concept as a theme is expressed by different responses for different questions by different participants.

Figure 2-1 Example of extracting a theme unit from the interview with a PWA

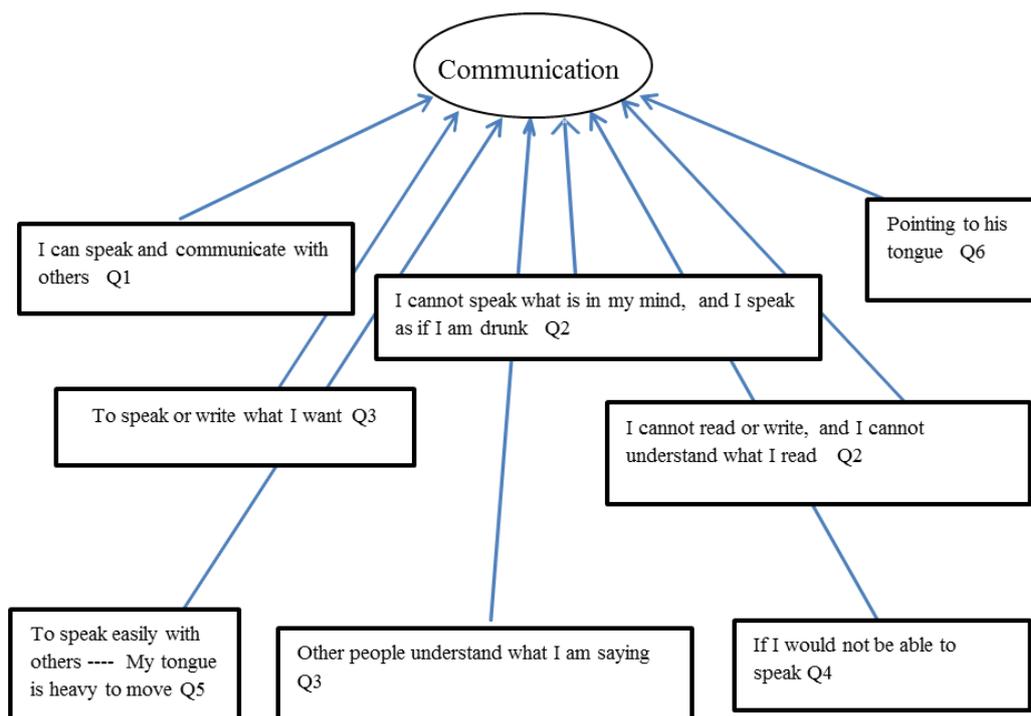


Table 2.6 below shows an example of the thematic analysis process of the note taking of the interview of the common report.

Table 2-6 An example of the thematic analysis process.

( For question one, what makes your life good? Is there anything else that makes it good? For question two, what makes your life bad? Is there anything else that makes it bad? Responses from three patients.)

Responses from the data/text	Statements	Codes/highlighted		Possible themes
Question 1: what makes your life good? Is there anything else that makes it good?		Coding involves assigning a particular theme or idea by a colour (the code) and then marking the code next to any component on the text that concerns the relevant theme	Frequency of the components/11 pt. Criteria for inclusion: to be repeated by 5 participants or more	
Pt1 .... I can <i>spea</i> k with others ...	... <i>I can spea</i> k with...	Communication (RED)		Communication
Pt2 ...I <i>ca</i> n drive my car...	<i>I ca</i> n drive...	Physical abilities (BLUE)		Physical abilities
Pt3 ...To <i>w</i> alk again without others' help...	... <i>To w</i> alk...			
Pt.4–Pt.11				
Question 2: What makes your life bad? Is there anything else that makes it bad?				
Pt1 ...I cannot <i>take care of my family</i> as before ...	... <i>Take care of my family</i>	Family relations (GREEN) + Physical abilities (BLUE)		Family relations
Pt2 ...I cannot <i>do things</i> by myself. I cannot go <i>back</i> to work and teach...	... <i>do things, back to work</i>	Work (YELLOW)+ Physical abilities (BLUE)		Career path
Pt3 ... I cannot go to the <i>Masjid</i> as before ...	... <i>go to masjid as...</i>	Religion (ORANGE)+ Physical abilities (BLUE)		Religion
Pt.4-Pt.11				
This is applied for each question and for the responses of each patient.				

The results of the thematic analysis revealed that different themes appeared to be important compared to those included in the draft questionnaire (**VR2**). The criteria for inclusion was the frequency of appearance; if a theme was mentioned by five participants or more out of the total of 11, these new themes/ sub-themes would be included in the version of the questionnaire for use first in the pilot study and then later in the main study. As a result of this analysis, the themes and sub-themes excluded were the career path, care givers relationships, isolation from society, and dependency on the rehabilitation and therapy progress; the sub-themes meeting the criteria from the excluded ones were redistributed among the remaining appropriate themes. The list of themes and sub-themes with examples is shown in **Appendix F**. Themes such as communication, physical difficulty, social and family relationships, religious duties, and emotions and feelings, with their sub-themes, were mentioned by five or more participants. Accordingly, a modified **VR2** of the questionnaire was then developed for use in the pilot study.

### **2.3.3 Phase three: pilot study**

#### **2.3.3.1 Rationale for the pilot study**

The primary aim of the pilot study for this modified version of the questionnaire (VR2) was to identify any potential problems and resolve them. This included evaluating the appropriateness of the existing questions for the targeted population by studying the way these subjects responded, the practicality of the measure for patients, and its face validity. In addition, there was a need to examine the questionnaire's accessibility (where it should be simple, not too lengthy and boring to complete or ask upsetting or annoying questions or unclear layout) and its acceptability (where the quality of data is assessed by completeness of the data and the score distributions of the patients), as suggested by Fayers and Machin (2007). Then, based on the information obtained, a revised version of the questionnaire was produced for the main study.

#### **2.3.3.2 The structure of the questionnaire (VR2)**

The modified version of the questionnaire (**VR2**) shown in **Appendix G** contains 48 questions distributed between six areas/ domains, as follows:

- A) Physical and daily life activities (11 questions)
- B) Communication (11)
- C) Interests and leisure (5)
- D) Religious activities (7)
- E) Social and family relationships (5)
- F) Feelings and emotions (9).

#### **2.3.3.3 The design of the scoring scale**

The majority of QoL instruments have been designed upon the principles of Likert scales (Fayers & Machin, 2007). In this study, a 5-point Likert scale was used, in which the response scale for each item/ question covered five different scale levels to reflect the degree of response level. This type of scale is commonly used as an attitudinal measurement scale in questionnaires developed by Rensis Likert in 1932. The labels for these five categories were

presented differently, such as using the degrees of difficulty, importance and how good the item was in the patient's view as a reference according to the nature of the domain under evaluation. This scale was accompanied with a visual analogue scale (VAS). The VAS used consisted of labelled boxes horizontally aligned, where each box presented the current state and was marked with the number of stars equal to its rank (i.e. 1 – could not do it at all had one star above its box; 5 – very easy had five stars). This provided for easy visualization by patients who do not read in their desirable selection (see **Appendix H**).

#### ***2.3.3.4 Participants in the pilot study for the questionnaire (VR2)***

Due to the difficulty in recruiting PWA, this version of the questionnaire was given to the same 11 participants who were recruited for the semi-structured interviews, although there was a two-week interval between sessions. The participants in this phase had the same criteria of inclusion for the semi-structured interview used earlier. For more details, (see **section 2.3.2.3.4**)

#### ***2.3.3.5 Administration of the questionnaire (VR2)***

The researcher explained the study to the 11 participants and reviewed the instructions with them to ensure their understanding. The questions were read aloud by the researcher and also presented in a written format on A4 paper in a large font size to help the participants who had eyesight problems to read comfortably, and also to make it easy for them in case they had forgotten their glasses, as recommended in the literature. One question was presented per page. The 5-point Likert scale was administered by the researcher, allowing for written (visual) and auditory information to be presented simultaneously to the patient for each item. The sessions lasted between 30-45 minutes.

#### ***2.3.3.6 Outcome of the pilot study of VR2***

The researcher followed the same criteria used previously for including the item, as it had to be mentioned and considered as either important or very important by five participants or more to be included.

The outcomes of the application of the questionnaire are presented in **Table 2.7**. This reveals that four questions/ sub-themes related to the physical and daily life activities (difficulty in travelling, playing with their children or grandchildren, styling hair for females, wearing

Ghutrah for males), in addition to one sub-theme related to feelings and emotions (nature of private life with the spouse), being added and one sub-theme (doing voluntary prayer) being deleted. The inclusion and exclusion here was based on the participants' reactions to these questions in terms of how relevant, clear and easy these questions were (acceptability and accessibility), and how applicable to the patients (appropriateness).

Table 2-7 Outcome of the pilot study of VR2

Themes	Sub-themes	Number of responses	An example
Physical and daily life activities	Difficulty in travelling (Added)	7/11	PT 7: I wish I could travel, so I can take the plane and go to Jordan to visit my son there (He had a son (autistic) who was treated at one of Jordan's rehabilitation centres)
	Playing with their children or grandchildren (Added)	5/11	PT 5: I can't play with my children as before because of the weakness in my hands and legs (she was a mother and had young children aged (3, 6 and 10 years old) and she used to play with them in their garden)
	Styling hair for females (Added)	7/11	PT 6: Because of problems moving my hands, I cannot even style my hair as I used to (she used to do this and style her daughter's hair but now it is the opposite)
	Wearing Ghutrah for males (Added)	7/11	PT 2: Since this problem happened, I wear sports clothes, because it is easier. Wearing the Thoub (traditional dress for men) and the Ghutrah needs more movement to manage it, especially the Ghutrah as it has to be held on the head properly
Feelings and emotions	Nature of private life with the spouse (Added)	6/11	PT 6: My relationship with my husband is not as before (because of her problem now, they have different rooms)
Religious activities	Doing the voluntary prayers (Sun-nah) (Deleted )	9/11 They do not do them	PT 1: Sometimes, it is even difficult to do the prayer at home (because of the physical difficulty he could only do the obligatory prayer)

This developed version of the questionnaire had some questions which were not clear enough or which needed clarification/ modification by the researcher, such as the exact type of clothing to which the question referred. At the end of the session, more questions were asked about the questionnaire itself. The participants were asked what they thought about the length of the questionnaire, and four of the 11 found it long. They were also asked about the difficulty of the questions and the scoring scale of the questionnaire they were asked and none of the patients reported any problems with the questions or with the scoring procedure. They reported that

most of the questions were clear and they had no difficulty understanding them. Moreover, 75% said that they did not need pictures to accompany the questions. No questions were found to be inappropriate. Accordingly, this information was used to restructure, rephrase, change, delete and add to the questions in the questionnaire in its new version. The full outcome of the questionnaire application is shown in **Appendix I**

### *2.3.3.7 The accessibility of the questionnaire's items:*

The researcher used supported communication to facilitate the responses of the participants. For this reason, the researcher read the question while gesturing and pointing to the written question and putting the scoring sheet in front of the participant. If necessary, the pictures used on the page were covered to help the participant to focus on the question. Repeating, rephrasing of the questions, and facial expressions were used in the administration. Only two participants (with severe aphasia) commented that the pictures were useful.

For participants who either could not read or had reading difficulties, the researcher showed one item per page while at the same time reading out each item so that they could rely on listening to the researcher, whereas participants with problems in understanding speech could rely mostly on reading the item. In this way, the participant would point to the selected response which the researcher would then mark. In addition to reading loud, the researcher used cues to facilitate their comprehension and response choice by using his SLP expertise to recognize the problematic items for the participant. These cues were administered gradually, for example by slower repetition of the item, rephrasing, and then personalising the item (how it may relate to them), until the examiner was assured that the participant had understood the meaning of the item well.

To reduce the reading demands, the length of the questions was also reduced, but the researcher provided examples to the participant which were not included in writing; instead, the researcher gave them verbally.

Five of the participants felt they had some or a little difficulty in understanding some of the items but they were facilitated by the researcher using repetition and gestures.

If the participant seemed unsure about how to answer a specific item, the researcher asked a follow up question to ensure the response and clarify his understanding of the choice (i.e. ‘So, it is difficult for you to do this... is it not?’ or ‘So, it is not easy for you to do this...’).

As a result of this process, the third and the final version of the questionnaire (VR3) was formed, which covered the same six areas/ domains but had 58 questions instead of 48, as follows: **A)** Physical and daily life activities had 13 questions, with two items added; **B)** Communication had 11 questions; **C)** Interests and leisure had eight questions, with three items added; **D)** Religious activities had nine questions with two items added; **E)** Social and family relationships had six questions with one item added; and **F)** Feelings and emotions had 11 questions with two items added. It should also be noted that the resulting themes and sub-themes consistently appeared in all the preparatory phases, and no redundancy occurred. Following this, VR3 (see **Appendix J**) was now ready to be used in the main study as the assessment tool for QoL in the form of an interview-administered questionnaire, and this will be covered in the next chapter.

## 2.4 Chapter summary

In summary, this chapter has described the three phases of developing the questionnaire. *Phase one*, which included reviewing existing measures of QoL, revealed that there were common domains of HRQoL measures which are similar to the ones recognized by WHO. These domains are: physical health, psychological health, level of independence, social relationships, environment, and spiritual/religious/personal beliefs, which are similar to the common QoL areas identified as potential domains for the intended questionnaire. From this review, three of the most common clinically used measures were selected: the SAQoL, the QCL, and the COAST, where they met the criteria set by the researcher. A cross-cultural adaptation process was applied to the selected questions to reflect Saudi culture and overcome the linguistic and dialect differences. *Phase two* involved the triangulation of the views of the professionals (SLP), ordinary Saudi people and Saudi PWA. This investigation was achieved via a survey sent as an online questionnaire to rank the importance of the questions suggested. The responses from both groups were collected, reviewed, and analysed using thematic analysis procedure. As a result of this analysis, the first version of the questionnaire was developed (VR1) with seven themes and 31 sub-themes. These questions were confirmed by sending a revised draft of this questionnaire again to the same groups using the same method. According to the similarities and differences found in the responses, the second version of the questionnaire (VR2) with six themes and 25 sub-themes was formed. As a result of the thematic

analysis of the semi-structured interviews on eleven Saudi PWAs, this scale was found to cover all possible themes for QoL for those patients and a modified version of the questionnaire (VR2) was developed with six themes involving 48 questions. In *phase three*, this version was evaluated through a pilot study and found to be accessible and acceptable by the Saudi PWA. Also, as a result, the final version of the questionnaire (VR3) was reached with six themes covered in 58 questions. In this phase, the process of developing a questionnaire using qualitative methods was completed and this questionnaire (VR3) was used in the main study for the more quantitative investigation, presented in the next chapter.

# Chapter 3: Methods and Results of the Main Study

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In this chapter, the quantitative part of the methodology is discussed. The first section describes the participants in the main study and the administration of the questionnaire. The next section provides the rationale for the data analysis, and for the missing or removed data which resulted in 40 items on 50 subjects, followed by evaluation of the psychometric properties of the questionnaire including its reliability and validity. There is then an explanation of how factor analysis (FA) was used to investigate the structure of the 40-item questionnaire and its underlying factors, using the varimax rotation method. The results of the FA were presented as a first rotation with a seven factor model of 40 items, and then the second rotation with a three factor model of 21 items. Then, the justifications and explanations for the dropped items from different domains as a result of the FA analysis are provided. Finally, this 21-item questionnaire was presented as the short version of the questionnaire.

## 3.1 The main study

VR3 was applied to the participants as a cross sectional study on two occasions. In this stage, the questionnaire was examined in regard to its validity and reliability. The data collected were analysed in order to investigate the underlying factors that the questionnaire represented and the items involved.

### 3.1.1 *Participants in the main study*

The main study was conducted on the same two sites as the pilot study, and the targeted population had the same inclusion and exclusion criteria, as noted in **Chapter two, Section (2.3.2.3.4)**. However, pilot study respondents were not allowed to participate in the main study because they already had prior knowledge of the study and might therefore introduce bias.

For the main study, all potential participants were informed about the details of the requirements of the study and consent was obtained prior to conducting the study; 74 eligible patients were approached for their consent from both sites, and 63 (85%) agreed to participate in the study. Of the 63 participants, 54 (86%) completed two interviews. Nine patients did not attend the second interview because: they were from outside the city and could not come to the hospital due to financial difficulties (three); they were unwilling to repeat the interview because they thought that it would be more like a therapy session (two); they could not come to the hospital because of the long journey time (two), or they were either hospitalised (one) or had died (one).

### ***3.1.2 Administering the questionnaire VR3***

Each administration session of the questionnaire ranged between 30-45 minutes and each interview was audio recorded for later reference and to check responses. The interviews were conducted either alone or with the patient's companion in a quiet room. If with a companion, this person was asked before the session not to participate, but was told that they would be able to comment after the session ended if they wished. This was because the study sought to investigate the patient's views and not those of a proxy. This problematic issue was thus avoided, as explained in the previous chapters.

In order to ensure that the measure/questionnaire was reliable and replicable, and to investigate its stability over time, a cross-sectional methodology approach was used. The questionnaire was administered twice to the participants, with a two to three week gap in between. According to Streiner and Norman (1995), for test/re-test reliability it is suggested that the appropriate time difference varies from one hour to a year depending on the task. The time difference in this study was thought reasonable as it was not too short to prevent the possibility of the patient remembering the questions and their earlier responses, and also not so long that there might be changes in the patient's health status (Fayers & Machin, 2007) or the patient might forget the study's task and lose interest. However, other reasons for this time gap were the difficulty of arranging appointments due to access and transportation problems, and conflicting patient appointments. Home visits were not appropriate due to cultural and social norms.

The questionnaire in its final version (VR3) (see **Appendix J**) was presented as it was in the pilot study for VR2 (see **Chapter two, Section 2.3.3.5**). The study was explained to the participants and the instructions were given to ensure their understanding of the task.

The participants were required to respond to the items on a five-point Likert scale (1-5), as explained earlier, which was presented in text and symbolic format in order to make it easier for PWA with reading difficulties. The patient's responses to each question were recorded on the response sheet.

## **3.2 Data analysis of the main study**

### **3.2.1 Rationale for data analysis**

The final version of the questionnaire (VR3) had items grouped under domains based on the outcomes of the triangulation process and the earlier pilot study. The analysis of the data was performed to investigate the structure of the inter-relationships and correlations between the items/ variables that represent the domains of the questionnaire, to confirm whether the items did in fact fall under those domains and whether the domains themselves were appropriate. To check the underlying structure of the questionnaire, a confirmatory factor analysis was employed by using the principal components extraction method. In this way, it was checked that items under the same domain were correctly grouped and measured the same construct, while items under different domains measured different constructs. This technique also identifies items that have little contribution to their domains.

### **3.2.2 Missing data**

After collecting responses for each participant and recording them on the scoring sheet, they were entered into SPSS (Statistical Package for the Social Sciences) software version 17.0. In order to ensure accuracy, the data were re-checked after every fifth entry. This was performed for all the data and all participants for both occasions.

Before further analysis was undertaken, the missing data were considered; this is necessary because bias may result from the data analysis. In terms of missing data<sup>5</sup> the

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<sup>5</sup> According to Fayers and Machin (2007), missing data include not only missing responses in which the answers are left blank, but also invalid or uninterpretable responses that have to be scored 'missing' for analysis of the data.

recommended criteria was for it to be <10% of the data (Fitzpatrick, Davey, Buxton, & Jones, 1998). Only the data of the patients who fully completed the questionnaire proceeded to the analysis. Four subjects were deleted because they had not responded to at least one question on one of the two occasions. Then, of the remaining 50 subjects, there were 18 items/ questions where people did not always respond, so these items were removed. The characteristics of the four subjects who were deleted are shown in **Appendix K**. Moreover, no single question was systematically missed; for example, one was missed as the patient had tired and wanted to finish the session sooner. Also, no difficulty was reported regarding problematic questions. Therefore, these missing data were not used during the analysis. **Table 3.1** shows the 18 missing items in relation to their domains and the possible reasons for being missing.

Table 3-1 List of the 18 missing items in relation to their domains as non-applicable and the possible reasons for being missing

Items	Item No.	Item /question	Domain	Possible reasons for being missed *Note: the numbers here are for patients who did not respond to those items
1	7A	Stand to get out of a chair	Physical & Daily life activities (3/13 ) items = 23%	General: - The patient became tired - The patient had other appointments, had to leave -The patient became nervous and wanted to finish the session -The patient had a driver instead Specific: 8A -13 patients of the sample were illiterate -Other 5 patients have hemiparesis/paralysis on the hand they use for writing/typing 12A - 23 patients of the sample were females who did not drive cars, while 27 patients were males -
2	8A	Write or type		
3	12A	Drive a car (M)		
4	2C	Do household activities	Interests and leisure( 4/8 )items = 50%	Specific: 2C - 15 out of the 23 female patients who used to do household activities as housewives had stopped doing that due to their physical difficulties  - 4 out of 27 male patients who used to do some gardening had stopped doing it after the incident due to physical difficulties 4C - 13 patients were illiterate - 4 patients felt that they did not understand what they read - 2 patients had reading difficulties 6C - 4 patients had no children - 3 patients were single - 8C - 13 patients were females who did not do any sport before or after the incident - 5 patients were over 70 years old who do not do any kind of sport even walking
5	4C	Do some reading, e.g. of the Quran		
6	6C	Play with children		
7	8C	Do some sport		
8	1D	To go to Mosque (Masjid) for five prayers (M)	Religious activities and duties (4/9) items = 44%	Specific: 1D, 3D - 23 patients were females, and so this item did not apply to them 2D - This was applicable for female patients only. 27 patients were males - 3 female patients could not pray at home because they believed that they would not do it properly 5D - 13 patients were illiterate - 6 patients had sight problems related to reading
9	2D	To do the prayers at home (F)		
10	3D	Do prayers you cannot do at Masjid (M)		
11	5D	Read the Quran as voluntary reading		
12	1E	Relationship with your partner (spouse)	Social relationships( 3/6 ) items = 50%	Specific 1E&8F - 10 patients were widowed - 3 patients were single - 1 patient was divorced 5E, 6E, 2F, 3F &4F - 22 patients were unemployed - 17 patients were retired - 3 patients were students 5E - 1 patient was self-employed
13	5E	Relationship with your boss at work		
14	6E	Relationship with your colleagues at work		
15	2F	Your status at work	Feelings and emotions ( 4/11 ) items = 36%	
16	3F	Your career path		
17	4F	Keeping in touch with your colleagues at work		
18	8F	Your private life with your partner		

Other demographic and health information about those patients who did not respond to these items can be found in the **Appendix L**.

The reasons given above in **Table 3.1** were extracted from: patients' medical notes, which included demographic information, their answers to the researcher questions, and observations made during interview, which were noted on the response sheet. The final data set thus included 40 items from 50 participants. The discussion about the missing data will be returned to in **Section 3.2.7**.

### 3.2.3 Participants

The demographic data of the 50 participants were examined. The severity of the aphasia was assessed by a translated version of the Frenchay Aphasia Screening Test (FAST) (Enderby, Wood, & Wade, 1987) with the following numbers and percentages resulting, as shown in **Table 3.2**.

Table 3-2 Percentages of severity of aphasia among the 50 participants

Severity (Score range)	N= 50	%
Mild (21-30)	19	38
Moderate (11-20)	21	42
Severe (1-10)	10	20

A descriptive analysis of the participants' characteristics is presented in **Table 3.3**. Educational, employment and socio-economic status information were obtained from the patient's medical record and checked with the patient. In regard to educational level,<sup>6</sup> less

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<sup>6</sup> The education levels of the participants were classified as follows: illiterate if the person cannot read or write; able to read and write is a person who has basic knowledge of numbers and the alphabet and can do basic math operations (adding and subtraction) or who has gained this knowledge by attending the old fashioned informal schooling (Katta-teeb), or a person who attended some formal education at elementary level but who quit schooling and did not complete the elementary level of six years; elementary refers to a person who attended and completed all six years at school and had the elementary school certificate at the end; for the intermediate education, this refers to a person who has the intermediate school certificate three years after the elementary level or who attended any year of this level (first, second and third grade); high school level is a person who has the high school certificate (three years) after finishing the intermediate level; university educated is a person who graduated from university after finishing high school and postgraduate educated is a person who has a postgraduate certificate (Master or PhD) after graduating from university.

than half (46%) of the participants were illiterate or could only read and write. This is not a surprising result for this age group of participants, whose education was limited and typical of the Saudi Arabia of 50 years ago, where education was not compulsory. Concerning employment, each participant was considered as: employed, unemployed, retired, or other if the previous categories were unsuitable, such as if the person owned a business or was a student with a part time job. Socio-economic status (SES) is problematic to determine due to the lack of a definite classification for income in Saudi Arabia, and is defined here as the monthly income received according to the participant's own estimate as low, average or high, as they themselves described it, and not against any reference given.

Table 3-3 The 50 Participants' Characteristics

Characteristics	N=50	%
<b>Age</b>		
Average	54 years	
Range	23-74 years	
<b>Gender</b>		
Male	27	54
Female	23	46
<b>Marital status</b>		
Single	3	6
Married	37	74
Divorced	1	2
Widow	9	18
<b>Post-time of onset</b>		
Average	37 months	
Range	3-60 months	
<b>Education level</b>		
Illiterate	13	26
Able to read and write	10	20
Elementary education	5	10
Intermediate education	3	6
Undergraduate/ university education	8	16
Postgraduate education	11	22
<b>Employment status</b>		
Employed	8	16
Unemployed	22	44
Retired	17	34
Other	3	6
<b>Socio-economic status (SES)</b>		
Low	4	8
Average	33	66
High	13	26
<b>Companion attendance</b>		
With a companion	33	66
Without a companion	17	34

The number of participants in each age group by gender indicated that this sample is a good representative participant group; this can be found in **Appendix M**.

### 3.2.4 Psychometric properties of the scale/questionnaire

In studies that include HRQoL measures, the measure used for research and clinical practice should be valid and reliable (Hays, Anderson, & Revicki, 1993). As this measure is intended to assess the QoL for Saudi PWA after stroke, which is considered HRQoL, it will be subjected to a psychometric evaluation of its properties, including its reliability and validity.

### **3.2.4.1 Reliability**

Reliability refers to the consistency of a measure and its stability over time; a reliable measure should give the same results each time it is applied to the same population and under the same conditions. The two aspects of reliability which apply to this study are internal consistency and test/re-test reliability, and these are discussed in the next section. Two aspects which were not considered for this study are inter-rater reliability (IRR), which refers to agreement between more than one rater on the same phenomena or individual under investigation. The other is equivalent/parallel forms reliability, referring to agreement on the results of two or more instruments (scales) used to measure the same concept but with different items. IRR was possible but not examined because the literature indicated that the IRR of QoL measures using similar approaches to the one used here was high. For this reason, in addition to time constraints, IRR was unnecessary for this study. Equivalent/parallel forms of reliability did not apply here because it was difficult to find two equivalent instruments that use different but equivalent test items to measure the same concept. Here, this would be the QoL for Saudi PWA after stroke with a similar culture and/or language. Additionally, no available alternative to the questionnaire was used and therefore only the internal consistency and test/re-test reliability were used to examine the scale's reliability.

#### **3.2.4.1.1 Internal consistency**

The questionnaire was designed to measure QoL, so the items under each section/domain in the questionnaire should be strongly correlated. Internal consistency was tested with Cronbach Alpha ( $\alpha$ ), which is widely used both for this and as an internal reliability test. Cronbach Alpha ( $\alpha$ ) indicates the item-total correlation, which shows to what extent these items measure the same aspect under that measured construct/dimension and to what extent they can be combined together into a single scale (Nunnally & Bernstein, 1994). Thus, it tests the homogeneity of the measure; within the range 0-1, the closer to one the results are, the stronger the correlation and reliability of the questionnaire, and vice versa. The Cronbach alpha in this study was  $\alpha = 0.97$ . According to Fayers and Machin (2007), for psychometric scales it is recommended that the Cronbach Alpha value should be above 0.8 (good) or 0.9 (excellent), while above 0.7 it is acceptable. This measure therefore shows sufficient internal consistency and the items under the six different domains of the measure as a whole are strongly correlated.

### **3.2.4.1.2 Test/re-test reliability of the questionnaire**

The other factor for which the questionnaire was investigated was test/re-test reliability, which refers to checking the correlation of the scores of the same individuals on two separate occasions over time. This questionnaire requires an acceptable level of test/re-test reliability and there should be no great difference between the scores of the participant on the two occasions for it to be reliable. This means that the higher the correlation in the test/re-test, the lesser the change that occurred. Streiner and Norman (1995) consider 0.75 as the minimum acceptable value for the reliability coefficient for an instrument, while Rosenthal and Rosnow (1991) claim that the clinical testing reliability coefficient value should be 0.85 or higher to be acceptable; however, a lower value can be accepted in experimental research.

The Pearson correlation coefficient (PCC) was used to measure the test/re-test reliability here because there was only one rater. The test/re-test reliability for this questionnaire was very good, with an overall correlation coefficient of 0.997. So it can be said, there is test re-test reliability with the same rater. Using Pearson's  $r$  does not assume normality of the variables. According to Bewick, Cheek, and Ball (2003), "Assumptions and limitations: The use of correlation and regression depends on some underlying assumptions. The observations are assumed to be independent. For correlation both variables should be random variables, but for regression only the response variable  $y$  must be random. In carrying out hypothesis tests or calculating confidence intervals for the regression parameters, the response variable should have a Normal distribution and the variability of  $y$  should be the same for each value of the predictor variable. The same assumptions are needed in testing the null hypothesis that the correlation is 0, but in order to interpret confidence intervals for the correlation coefficient both variables must be Normally distributed. Both correlation and regression assume that the relationship between the two variables is linear." (p.451). The correlation is, as can be seen 0.997. A nonparametric Spearman correlation is 0.993. The data are not normally distributed, (Shapiro-Wilk = 0.936,  $p=0.006$ ). Also, Field (2009), stated "A significant value indicates a deviation from normality, but this is notoriously affected by large samples in which small deviations from normality yield significant results."(p.793).

In spite of concerns that PWA may not be reliably used for patient-reported outcome measures, the data were checked and rechecked, and found to be similar to other studies' findings, which found high test/re-test reliability when aphasia friendly outcome measures are used. Both SAQoL and the Burden of Stroke Scale (BOSS) include aphasia friendly features and demonstrated test/re-test reliability from 0.78-0.99, while for SAQoL-39 the range was 0.89-0.98 (Doyle et al., 2007; Hilari et al., 2003).

#### ***3.2.4.2 Validity evaluation of the scale /questionnaire***

The validity or validation of instruments is the process that determines whether the instrument measures what it is designed to measure. This process includes both face and content validity, which was undertaken previously during the developmental stages of the questionnaire and its triangulation and cultural adaptation process. In addition, the process measures construct validity, which examines the theoretical relationships of the items to each other and to the developed scale/questionnaire.

##### ***3.2.4.2.1 Construct validity of the questionnaire***

For the purpose of evaluating this scale, there is a need to investigate the construct of this measure/ scale by exploring how many factors were involved which have an effect on QoL, how different items relate to these factors and how the loads of the identified items for each factor can define the content and meaning of these factors as they construct the measure/ scale. This can be achieved by determining the sets of items in the questionnaire, identifying the nature of the relationships between scores on the different items, and identifying the factors (dimensions) that best account for the data patterns. Measuring the construct validity of this scale ensures that it measures the underlying construct and examines the theoretical relationship of the items to each other. It emphasizes the meaning of the responses to the scale to ensure that the scale measures the underlying construct and nothing else. Construct validity is evaluated by within-scale analysis by assessing the internal consistency and ensuring that items are interrelated and measure different aspects of the same construct. It is different from Cronbach alpha in that it is based on item to total on a multi-item scale. FA is commonly used to assess the construct validity of QoL scales and therefore exploratory factor analysis was used for this purpose because the measured responses were based on underlying factors and no prior knowledge of the structure of the questionnaire was given. The correlation between these items was then used as a starting point to ascertain the underlying structure.

### **3.2.5 Evaluation of the scale using FA**

The developed scale/ questionnaire had items/ questions grouped together under certain domains as a result of reviewing the existing measures and the triangulation process that was done previously. FA helps the researcher to check whether the items included do in fact fall under those domains and whether the domains themselves are appropriate.

FA examined the structure of the developed measure/ questionnaire and the responses to it, which, according to Field (2009), is used when a questionnaire is developed to measure underlying variables. This helps to reduce the original data to a more manageable size while retaining as much of the original information as possible. FA reveals the correlation between variables, whilst also ensuring that the items under the same domain are correctly grouped, measure the same construct, and are applied to all the domains involved. It also ensures that items in different domains measure different constructs. As a result of the FA, a model for the number of factors can be estimated. This model represents the correlations between the items and reflects the relationship between the different factors. In order to perform FA, data should meet certain psychometric requirements, one of which is the value of the Kaiser-Meyer-Olkin (KMO) as a measure of sampling adequacy.

#### **3.2.5.1 Sampling adequacy**

The value of the KMO as a measure of sampling adequacy is used in FA to reveal the essential assumptions of a study, so that variables can be grouped into a smaller number of underlying factors. According to Kaiser (1960), the minimum acceptable value for KMO should be more than 0.5; below that, more data needs to be collected or the variables that should be included need to be reviewed. Moreover, according to Hutcheson and Sofroniou (1999), values are classified as average when they range between 0.5-0.7, good between 0.7-0.8, excellent between 0.8-0.9, and superb when above 0.9. Thus, values of greater than 0.5 are required for a satisfactory FA to progress. The results for this data were a KMO value of 0.86, indicating that FA would be appropriate and useful with this data, and that the sample was adequate.

#### **3.2.5.2 Statistical approach for FA**

In this study, there is a potential group of factors that may have some influence on the QoL for Saudi PWA after stroke. This study's hypothesis is that the QoL of Saudi PWA

may differ from Western societies (European and North American where the overwhelming majority of studies have been conducted) due to the differences in cultural context (Muslim and Arabic), views about health, diseases and different social norms. This study aimed, firstly, to explore the factors that affect QoL for Saudi PWA after stroke, including issues which are specific to Saudi society, such as cultural and religious issues and from the resulting outcomes. From this, the second aim was obtained, which was to develop an assessment tool for QoL for Saudi PWA. Its validity and reliability were examined and it facilitated the investigation of the relationship between QoL and other predictors.

In order to explore and examine this study's hypothesis, principal components analysis (PCA) was used to decompose these original variables within factor analysis (Dancey & Reidy, 2007). Tabachnick, Fidell, and Osterlind (2001) recommend the use of PCA as the first step in FA to extract the initial sets of factors. This procedure is used to ensure that each domain measures one underlying component, so only the important factors will be extracted. According to Field (2009), this will guarantee that, "most variables have high loading on the most important factor, and small loadings on all other factors."(p.438)

One method of determining the number of factors is to use the rule of eigenvalues, where the greater than one rule ( $>1.0$ ) is commonly used as a first step. According to Hair, Black, Babin, Anderson, and Tatham (2006), this criterion prompts the researcher to accept factors only if they have an eigenvalue greater than 1.0. Another more subjective method is the scree plot, on which continuous eigenvalues are drawn and important factors can be separated from other factors by a breaking point (or point of inflexion).

After that and in order to help the researcher in the interpretation of the patterns of data at the initial factor solution stage, Orthogonal varimax rotation for the data was used to achieve a simplified model as recommended by Tabachnick et al. (2001). This type of rotation provides the extracted factors with new (post-rotation) loadings of the original variables; these loadings are equal to the correlations between the factors and items. Also, its objective is to maximize the amount of variance explained by each factor involved, so the varimax maximizes the loading of each item on a single factor, while minimizing its loading on the remaining factors. It makes the large loadings larger and the small loadings smaller. As a result, a new set of loadings for the factors will be obtained, but each factor will have fewer items with high values. However, the same total amount of variance that

was obtained before is still explained by these new factors and, as a result, the varimax leads to a more meaningful and simpler factor pattern.

### 3.2.6 Results of the FA

#### 3.2.6.1 Results of the first varimax rotation

After applying varimax rotation, PCA resulted in seven factors that accounted for 82% of the accumulated variance (see **Table 3.4**). The first two factors explained 53% of the variance, with 29% and 24% respectively, and the third, fourth, fifth and sixth together explained the remaining 28% of the variance with small percentages of 8%, 7%, 5% and 4% respectively.

Table 3-4 Total variances of the first varimax rotation explained

Component	Initial Eigenvalues			Extraction Sums of Squared Loadings			Rotation Sums of Squared Loadings		
	Total	% of variance	Cumulative %	Total	% of variance	Cumulative %	total	% of variance	Cumulative %
1	20.221	50.551	50.551	20.221	50.551	50.551	11.497	28.743	28.743
2	3.574	8.934	59.486	3.574	8.934	59.486	9.856	24.641	53.383
3	3.047	7.618	67.103	3.047	7.618	67.103	3.047	7.617	61.001
4	1.963	4.907	72.010	1.963	4.907	72.01	2.662	6.654	67.655
5	1.458	3.646	75.656	1.458	3.646	75.656	2.119	5.298	72.952
6	1.346	3.366	79.022	1.346	3.366	79.022	1.841	4.601	77.554
7	1.049	2.622	81.645	1.0498	2.622	81.645	1.636	4.091	81.645
8	0.911	2.277	83.922						
9	0.724	1.809	85.731						
10	0.668	1.669	87.400						
11	0.610	1.525	88.926						

Total variance of the first 2 factors

Total variance of 7 factors

Whether there is a need for another rotation depends on the stability of the factorial model extracted, meaning that this model should not involve items with loads of less than 0.4 and items with cross loadings, and there should be at least one item loading per factor in this model (Kaiser, 1960). Accordingly, the selection of these items under each factor was based on items being selected only if they were strongly related to one factor with a loading of 0.4 or above, while other items were dropped under that factor for cross or double loading, and any items that were loaded less than 0.4 were deleted (Kaiser, 1960). This criterion was used because it guarantees good factor saturation (Ferguson & Cox, 1993). This rotation led to seven factors with their items, and their distribution is explained in **Table 3.5**.

Table 3-5 Rotated component matrix –first rotation with seven factors results

Items	Rotated component matrix	Component						
		1	2	3	4	5	6	7
Q5A	balance when bending over or reaching	.866						
Q3A	cleaning yourself at the toilet and covering yourself	.840						
Q13A	being independent	.836						
Q4A	walking by yourself	.830						
Q2A	taking a bath or shower	.826						
Q6A	climbing the stairs	.822						
Q1A	getting dressed	.821						
Q10A	styling your hair/Guttrah	.817						
Q11A	walking for a while on a daily basis	.817						
Q6D	doing ablutions (wad-ou)	.808						
Q9A	doing a zip/a button	.770						
Q8D	eating with the right hand	.694						-.408
Q9D	shaking hands with the right hand	.683	.418					
Q7C	travelling to other places	.618		.414				
Q1C	following the news/sports on TV	.604	.446					
Q11B	showing you do not understand		.869					
Q3B	friends understanding you when you talk		.861					
Q2B	your family understanding you when you talk		.842					
Q8B	telling your life stories		.841					
Q4B	speaking clearly on the phone		.829					
Q9B	getting other people to understand you		.825					
Q1B	expressing your opinion	.465	.802					
Q6B	joining in conversation		.799					
Q5B	speaking to other people (strangers)	.468	.791					
Q7B	finding the words you want to say		.716					
Q10B	understanding simple commands	.403	.648					
Q4D	reading the Holy Quran (Aayat) during the prayers	.448	.556					
Q1F	your feelings toward accepting people to you		.527					
Q7D	memorizing (Aayat) (Du-aa) prayers			.732				
Q5C	sharing /participating in your community activities			.710				
Q3C	getting out of the house and doing things	.523		.644				
Q10F	your family's confidence in you			.478				.450
Q4E	your neighbours/friends				.864			
Q3E	your relatives				.727			.410
Q11F	your life now				.708			
Q6F	being treated like a normal person					.772		
Q7F	your values being unchanged					.764		
Q9F	being supported by the people around you						.784	
Q5F	keeping in touch with your friends							.787
Q2E	your relations with your family members				.457			.586
	Extraction Method: Principal Component Analysis Rotation Method: varimax with Kaiser Normalization	a. Rotation converged in 13 iterations						

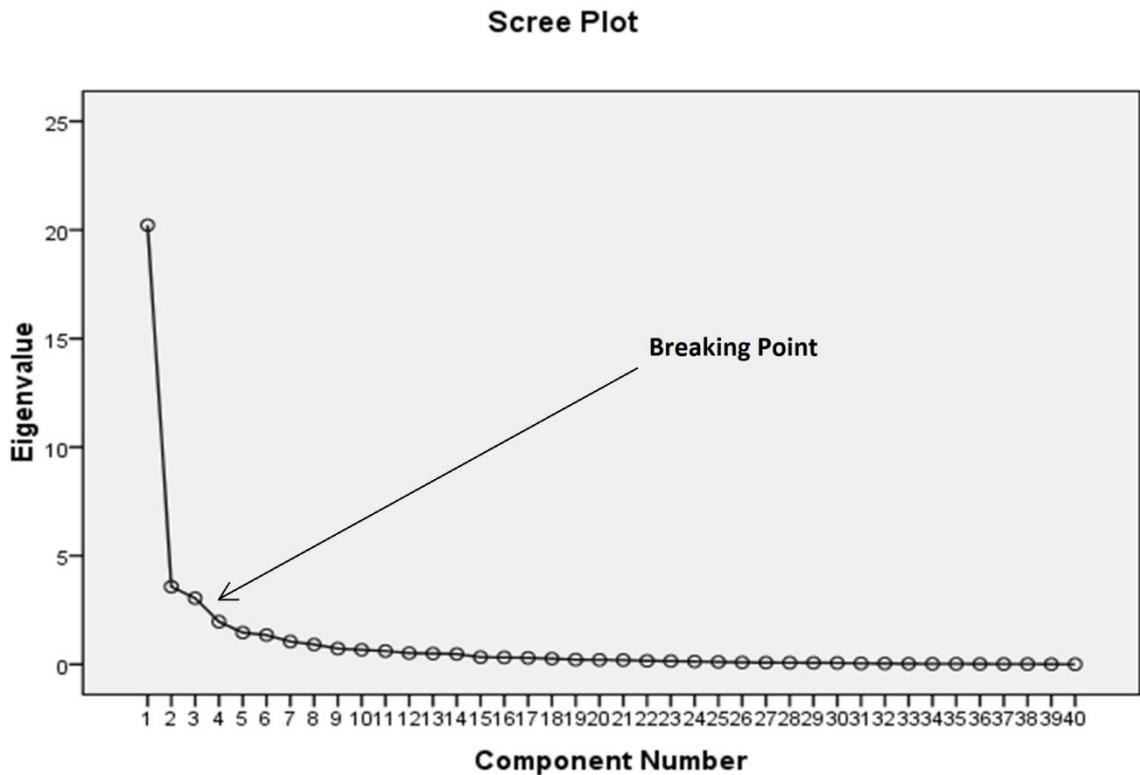
The main conclusion to be drawn from the FA was that it did not confirm the a priori grouping of items into domains. The seven-factor model did not reflect all domains well; for example, social relationships contributed very little, having only three items with loadings above 0.4 among the seven factors. Also, the grouping of some domains together was conceptually not clear, such as in factor two, the grouped items on communication, interests and leisure, religious activities, and feelings and emotions domains, in which items from more than one domain sometimes come under one factor. Furthermore, at least one domain can be seen contributing to more than one factor. These 40 items were distributed as follows: 13 items from the communication domain, ten from physical and daily life activities, seven from the feelings and emotions domain, five from religious activities and duties, three from family and social relationships and two from the interest and leisure domain.

However, the resulting seven-factor model, as shown in **Table 3.5**, was unstable as there were 12 items with cross-loading, and one item with a loading of  $<.4$  in factor six with a negative value. Also, after factor three it can be noticed that the number of items loaded per factor started to decrease: factor four had three items, factors five and seven had two items each, and factor six only one. Thus, these items needed to be removed in order to improve the stability of the model, and so a further factor analysis was undertaken.

#### **3.2.6.2 Results of the second varimax rotation**

FA was repeated in order to obtain a better and more stable solution which represents the original factors involved. To determine the number of factors expected for the new factorial model, the scree plot was used. This plot showed that only three factors should be chosen for extraction, as illustrated in **Figure 3.1** below. According to Field (2009), in the scree plot an inflexion curve usually occurs after the three factors where the curve begins to tail off; after the fourth factor there is another drop before a stable plateau is reached. The scree plot shows the eigenvalues of the correlation matrix in descending order. The number of factors extracted will equal the number of eigenvalues that are before the last drop on the eigenvalue magnitude. It can be seen that the breaking point of the scree plot arguably occurred after the third component.

Figure 3-1 Scree plot of the 2nd rotation



The number of extracted factors is also supported by applying PCA and this also resulted in the total variance being explained by three factors, as illustrated below in **Table 3.6**. In this table, it should be noted that factor one accounted for  $\approx 31\%$  of the variance, factor two accounted for  $\approx 27\%$  and factor three only 9.6%. These three factors together accounted for 67% of the variance.

Table 3-6 Total variance explained of the second varimax rotation

component	Initial Eigenvalues			Extraction Sums of Squared Loadings			Rotation Sums of Squared Loadings		
	Total	% of variance	Cumulative %	Total	% of variance	Cumulative %	Total	% of variance	Cumulative %
1	20.221	50.551	50.551	20.221	50.551	50.551	12.337	30.842	30.842
2	3.574	8.934	59.486	3.574	8.934	59.486	10.673	26.683	57.525
3	3.047	7.618	67.103	3.047	7.618	67.103	3.831	9.578	67.103
4	1.963	4.907	72.010						
5	1.458	3.646	75.656						
6	1.346	3.366	79.022						
7	1.049	2.622	81.645						
8	0.911	2.277	83.922						
9	0.724	1.809	85.731						
10	0.668	1.669	87.400						

Extraction Method: Principal Component Analysis

In the Rotated Component Matrix, certain conditions should be met for the factors in the table. Firstly, these three factors are independent and, secondly, their factor loadings should be more than 0.4. By looking at the Rotated Component Matrix shown in **Table 3.7**, it can be seen that these two conditions were met. Also, from the table it can be seen that factor one was represented by six items from physical and daily life activities and only one from the interests and leisure domain out of the seven items (1A, 2A, 4A, 5A, 6A, 13A, 7C). Factor two reflected the communication domain in its all seven items (1B, 3B, 4B, 6B, 7B, 8B, 11B, 13B), while factor three was represented by five items from the feelings and emotions domain and two from family and social relationships (5F, 6F, 9F, 10F, 11F, 2E, 3E), and no item loadings were  $<.4$ .

Table 3-7 Rotated component matrix –second rotation with three factors result

Item	Item statement/question	Component		
		1	2	3
Q4A	Walking by yourself	.890		
Q5A	Balancing when bending over or reaching	.886		
Q6A	Climbing the stairs	.885		
Q13A	Being independent	.864		
Q2A	Taking a bath or shower	.841		
Q1A	Getting dressed	.835		
Q7C	Travelling to other places	.755		
Q10F	Your family's confidence in you			.450
Q3B	Friends understanding you when you talk		.876	
Q8B	Telling stories of your life		.849	
Q11B	Showing you do not understand		.843	
Q6B	Joining in a conversation		.815	
Q4B	Speaking clearly on the phone		.803	
Q1B	Expressing your opinion		.803	
Q7B	Finding words that you want to say		.736	
Q9F	Being supported by the people around you			.767
Q3E	Your relations with your relatives			.741
Q2E	Your relations with your family members			.703
Q5F	Keeping in touch with your friends			.505
Q6F	Being treated like a normal person			.439
Q11F	Your life now			.426

Factor 1:  
6 A Qs from Physical & daily life activities domain.  
+ 1 C Q from Interests and leisure domain

Factor 2:  
All 7 B Qs from communication domain

Factor 3:  
5 F Qs from Feelings & Emotions+  
2E Qs from family & social relationships

Extracted method: Principal Component Analysis –Rotation Method: varimax with Kaiser Normalization. Rotation converged in 6 iterations. Where A qs for physical & daily life activities, B qs for communication, C qs for interests & leisure, D qs for religious activities, E qs for feelings & emotions and Fqs for family & social relationships.

The factor model started to stabilize at the three factor solution. This three-factor model was conceptually acceptable as each factor represented mainly one domain in its items. At this stage, 67% of the variance was accounted for, and so no further extraction was necessary. In conclusion, the results of the FA indicated that not all of the 40 items of the questionnaire significantly contributed to the overall score, which resulted in an unstable, unclear factorial model. This resulted in a more stable and acceptable three-factor model represented by only 21 items distributed between the three factors as a shorter version of the questionnaire, shown in **Appendix N**. As this study aimed to develop a questionnaire/scale to be used as measure of the QoL of Saudi PWA, this three factor model was the best representation of the original model and had the least number of factors extracted. As a result, the final list of the 21 items was produced, as shown in Table 3.8.

Table 3-8 The final list of items (21-items)

	Item	Statement of the item
Mobility	1	Walking by yourself
	2	Balancing when bending over or reaching
	3	Climbing the stairs
	4	Being independent
	5	Taking a bath or shower
	6	Getting dressed
	7	Travelling to other places
Communication	8	Having your friends understand you when you talk
	9	Telling stories about your life
	10	Showing others that you do not understand
	11	Joining others in a conversation
	12	Speaking clearly on the phone
	13	Expressing your opinion
	14	Finding the words that you want to say
Social support and participation	15	Your relationship with your relatives
	16	Your relationship with your family members
	17	Your family's confidence in you
	18	Being supported by the people around you
	19	Keeping in touch with your friends
	20	Being treated like a normal person
	21	Your life now

### ***3.2.6.3 Items dropped from the 40 items questionnaire in reducing it to 21 items***

It was decided to develop a briefer questionnaire consisting of just 21 items –the seven with highest loading on each of the three factors in the three factor analysis. As a final result of FA, 19 items out of the 40 items questionnaire were dropped from several domains. Interestingly, one complete domain, religious duties and activities (D), was dropped. Three out of four items were dropped from the interests and leisure domain, while four out of a total of 11 were dropped from communication. Four items out of 13 were also dropped from the physical activities dimension, and one out of three items was lost from social relationships; finally, feelings and emotions lost two out of 11 items, as shown in **Table 3.9**.

Table 3-9 The 19 items dropped following the second rotation of the FA

S. No	Item	Statement of the item/question	Domain
1	Q3A	Cleaning yourself at the toilet and covering yourself	Physical and daily life activities
2	Q9A	Doing a zip /a button	
3	Q10A	Styling your hair/ Guttrah	
4	Q11A	Walking for a while on a daily basis	
5	Q2B	Your family understanding you when you talk	Communication
6	Q5B	Speaking to other people (strangers )	
7	Q9B	Getting other people to understand you	
8	Q10B	Understanding others' simple commands	
9	Q1C	Following the news/sports on T.V.	Intrests and leisure
10	Q3C	Getting out of the house and doing things	
11	Q5C	Sharing/participating in your community activities (marriage...)	
12	Q4D	Reading the Holy Quran (Aayat) during prayers	Religious activities and duties
13	Q6D	Doing ablutions (Wadou)	
14	Q7D	Memorizing (Aayat) supplications (Du-aa) in prayer	
15	Q8D	Eating with the right hand	
16	Q9D	Shaking hands using the right hand	
17	Q4E	Your relationship with your neighbours and/ friends	Social relationships
18	Q1F	Accepting people to you	Feelings and emotions
19	Q7F	Your values not being changed	

### 3.2.7 Why items were dropped

This section attempts to explain why certain items were dropped from the questionnaire following FA.

#### 3.2.7.1 Religious items

First, the religious domain lost nine items in two stages; four were lost because items were considered missing during the data check stage, and five during the FA stage. The four dropped items were: Q1D going to the mosque for five prayers (M); Q2D doing prayers at home (F); Q3D doing prayers that could not be done at the mosque (M), and Q5D voluntarily reading the Quran.

Initially, it was assumed that this domain would have a significant impact on the QoL for Saudi patients with aphasia, and this assumption was also supported by the literature on the religious aspect of measuring the QoL for PWA, as mentioned previously in chapter one. In addition, these items were drawn from the triangulation process completed at the questionnaire development stage, which included the views of professionals, ordinary people who knew or lived with someone with aphasia, and the views of aphasic patients themselves, plus the input from the pilot study of the questionnaire, as mentioned earlier.

There is a likely non-statistical explanation for not including the first four religious domain items. These were only four out of nine items ( $4/9=44\%$ ) of the whole domain, as explained previously in **Table 3.1, Section 3.2.2**. From this table, it is clear that they were gender-related for the first three questions (1D, 2D, 3D). For items 1D and 3D, it is obligatory for the man in Islam to do all five prayers in a group at the mosque (Masjid). He may be excused from doing it if he is sick or travelling, but if he cannot perform the prayer at the Masjid he must do it at home if possible. For women, however (question 2D), the woman is only allowed to perform the five daily prayers at home. Therefore, these questions are clearly gender-based, and the impact of the gender on the responses to the religious activities items will be discussed later in this chapter under **Section, 3.2.7.3**.

The last of the first four religious domain items to be dropped, 5D (voluntarily reading the Quran), is basically related to the patient's ability to read, in addition to the patient's ability to read/write after aphasia, bearing in mind that it is a voluntary reading. Also, it

is clear that the patient's physical and cognitive abilities are affected by aphasia due to stroke alongside other health problems related to age, such as vision, and this may encourage the patient to avoid certain tasks such as voluntary reading.

The remaining five items of the religious domain were dropped following the second varimax rotation, and there are different explanations for this. Statistical explanations should first begin by looking at the correlation matrix of the 40 items shown in **Appendix O** to investigate the strength of the relationship between the religious items involved and QoL.

In regard to the question of QoL asked, it was found that this particular question is a very useful one for QoL measures. In the literature, questionnaires for assessing QoL usually include multiple questions; however, few scales rely upon a single global question such as "How do you rate your QoL? Or what is your overall QoL over the last week?", while other questionnaires combined both specific and general questions (Fayers & Machin, 2007). Therefore, for this developed questionnaire, one general/ global question was included, which is Q11F (how is your life now?) to express their general QoL, in addition to other questions related to dimensions under investigations. Moreover, this question remained through the process of developing the questionnaire and the triangulation process and in the pilot studies done earlier.

From the correlation matrix of the 40 items (**Appendix O**), the correlation matrix for the religious items revealed that the QoL question Q11F (how is your life now) had a weak correlation with the five religious variables (Q4D, Q6D, Q7D, Q8D, Q9D) with values of 0.25, 0.27, 0.14, 0.12, and 0.24 respectively. So, QoL had a weak correlation with all the religious items (i.e. Q1D, Q2D, Q3D, Q4D, Q5D, Q6D, Q7D, Q8D and Q9D) with values of 0.08, 0.05, 0.01, 0.25, 0.18, 0.27, 0.14, 0.12 and 0.24 respectively. None of these correlation coefficients were significant, that may be why these items were dropped.

The second statistical explanation for the exclusion of the five religious items is by investigating these dropped items by exploring the correlation between these scores on these items and the others. The correlation matrix shows the strength of the relationship between variables. From the correlation matrix in **Table 3.10**, this set of religious items indicates that there are eight correlations in the matrix greater than 0.3 (highlighted). As can be seen, item one (4D-reading the Holy Quran (Aayat) during the prayers) is strongly correlated with other variables: two (6D-doing the ablutions (Wadou), three (7D –

memorizing (Aayat) and supplications (Du-aa) in prayer), four (8D –eating with the right hand) and five (9D –shaking hands using the right hand). These had values of .64, .57, .54, .55 respectively, which reflects the strength of the relationship between variable one and the other variables. This is applied for other items, where the 8D correlates with 6D and 7D with .56 and .30 respectively, while item 9D correlates with 6D and 8D with .69 and .84 respectively.

It can be concluded that these items had a good correlation with each other as a group under the religious activities domain. Furthermore, it suggests that the correlation between these items under this domain was not the reason for these items to be dropped. This may suggest that a good correlation between these items does not necessarily mean they should have good correlation with QoL.

Table 3-10 Correlation matrix for the five religious items dropped

	Item	Q4D	Q6D	Q7D	Q8D	Q9D
1	Q4D	1.00				
2	Q6D	0.64	1.00			
3	Q7D	0.57	0.28	1.00		
4	Q8D	0.54	0.56	0.30	1.00	
5	Q9D	0.55	0.69	0.27	0.84	1.00

The third statistical explanation for the exclusion of the five religious items was derived from the exploration of the whole rotated component matrix, extracted by PCA when the second varimax was performed. This is shown in Table 3.11, where all the coefficients were displayed, not just those  $>.4$ . These smaller items were not displayed in the PCA at the second varimax rotation in the first place because of the condition imposed that items with loads  $<.4$  would not be displayed. This meant that only the items with the highest loadings on these three factors were displayed. However, **Table 3.11** displays the loads of the dropped religious items, and reveals that each of these items had different loads (cross-loads) between the three factors. It is suggested that each item could have belonged to an underlying factor other than their original one, as both items 1(4D) [reading the holy Quran (Aayat) during prayers] and 3(7D) [memorizing (Aayat)] and supplicating [(Du-aa) in prayer] had their highest loads under factor two, communication, with .636 and .514, respectively. However, these loads were still smaller than the lowest item extracted, since

the highest and lowest loads that represented this factor were .876 and .736, respectively. Similarly, the loads of item 2(6D) [doing the ablutions (Wadou)], item 4(8D) (eating with right hand) and item 5 (9D) (shaking hands with the right hand) were .750, .669, .692, respectively. These came under factor one (physical activities) but the values were still smaller than the lowest loads under this factor, where the loads of the extracted items ranged between .755-.890. This result may suggest that the five dropped religious items could have been redistributed under another domain other than the domain that they belonged to at the time of the measure.

Table 3-11 Segment of the rotated component matrix for the five dropped religious items

.	Item		Component		
			Factor 1	Factor 2	Factor 3
1	4D	Read the Holy Quran (Aayat) during the prayers	.481	.636	.053
2	6D	Do ablution (wadou)	.750	.316	.248
3	7D	Memorizing (Aayat) and (Du-aa) in prayer	.256	.514	-.004
4	8D	Eating with the right hand	.669	.311	-.129
5	9D	Shaking hands with the right hand	.692	.398	.061
Extraction Method: Principal Component Analysis Rotation Method: varimax with Kaiser Normalization. a. Rotation converged in 6 iterations					

In summary, it can be said that the dropping of the religious domain is linked to the weak correlations found both between its items and to QoL, which it does not mean just one item, here, but also the complete set of 54/40/21 items are a measure of QoL, or due to the inter-correlation of these items between the domains, as with the cross -loading of other factors.

### 3.2.7.2 Other items

Other domain items were dropped, as shown in **Table 3.9** above. These items belonged to: the physical and daily life activities (3A, 9A, 10A, 11A) and communication domains (2B, 5B, 9B, 10B), both of which lost four items; the interest and leisure domain, which lost three items (1C, 3C, 5C); the feelings and emotions domain, which lost two items (1F, 7F), and the social and family relationships domain, which lost one (4E).

To investigate these dropped items, the same procedure as for the religious items was followed. The correlations of these variables/ items are shown in **Appendix O** of the correlation matrix of the 40 items. This correlation matrix reveals that there is a weak correlation between these items under the same domain, and also their correlations with QoL are weak. However, this matrix shows that the next highest correlation between these items in this correlation matrix was 0.93 between Q1A (getting dressed) and Q2A (taking a bath or shower). These were not dropped and this correlation is significant at the 1% level. On the other hand, the correlation coefficient between Q1A and QoL Q11F (how is your life now) was 0.32 which is significant at the 5% level; however, the correlation coefficient between Q2A and QoL was 0.24, which is not significant at the 5% level. Thus, it can be said that these items may be dropped because of their weak correlations between each other under the same domain and due to their weak correlation with the QoL. For all the other items dropped, the correlation was weak between these items and other items under the same domain, and also with the QoL.

### ***3.2.7.3 Comparison of dropped items by gender***

In the preceding sections, statistical and non-statistical explanations were given for the dropped items. In this section, potentially statistically significant differences between gender on the dropped items and on QoL were examined. This was performed using an independent sample t test as there were two groups, males and females, and it was necessary to find the difference on a continuous variable, i.e. the dropped items and QoL.

The t-test does not require that the underlying distribution is normally distributed. All that it requires is that the *means* across the samples across and in this case the central limit theorem guarantees that in the limit they will. Except where there is substantial skewness these results will rapidly converge to a t-test. **Table 3.12** shows the results of a two sample t test.

Looking at QoL (Q11F) on the last row of the table, the average value for male patients was 3.7 and that for females was 3.6. Even though the average QoL for males was slightly higher than for females, there was no statistical significance difference between male and female patients on QoL, with a t-test p value of 0.675 ( $>0.05$ ).

Table 3-12 Comparison of the dropped items by gender

Item	Gender	N	Mean	Std. Deviation	Two tailed p from t test
Q3A	male	27	4.0	1.4	0.855
	female	23	3.9	1.1	
Q9A	male	27	3.2	1.3	0.254
	female	23	3.6	1.2	
Q10A	male	27	3.6	1.1	0.211
	female	23	3.1	1.3	
Q11A	male	27	3.5	1.2	0.514
	female	23	3.2	1.2	
Q2B	male	27	3.8	1.2	0.654
	female	23	4.0	1.0	
Q5B	male	27	3.0	1.5	0.612
	female	23	2.8	1.1	
Q9B	male	27	3.3	1.4	0.977
	female	23	3.3	1.1	
Q10B	male	27	4.2	1.0	0.628
	female	23	4.0	.8	
Q1C	male	27	3.9	.9	0.067
	female	23	3.3	1.1	
Q3C	male	27	3.6	1.0	0.091
	female	23	3.1	1.1	
Q5C	male	27	3.3	1.2	0.072
	female	23	2.7	1.1	
Q1D	male	27	3.1	1.3	* 0.178
	female	1	5.0		
Q2D	male	0 <sup>a</sup>			*
	female	22	3.5	.9	
Q3D	male	27	3.6	1.2	* 0.093
	female	2	5.0	0.0	
Q4D	male	27	3.4	.9	0.704
	female	23	3.3	.9	
Q5D	male	21	3.1	1.1	0.467
	female	12	2.8	1.0	
Q6D	male	27	3.4	1.2	0.389
	female	23	3.6	1.0	
Q7D	male	27	3.1	.9	0.101
	female	23	2.7	.9	
Q8D	male	27	3.2	1.1	0.420
	female	23	3.4	1.1	
Q9D	male	27	3.3	1.1	0.161
	female	23	3.7	1.1	
Q4E	male	27	4.0	.7	0.191
	female	23	4.2	.6	
Q1F	male	27	4.3	.7	0.664
	female	23	4.2	.9	
Q7F	male	27	3.7	.8	0.135
	female	23	4.0	.8	
Q11F	male	27	3.7	.9	0.675
	female	23	3.6	.7	

\*Too few female subjects

It can therefore be said that there are some gender specific items (1D, 2D and 3D) and unsurprisingly there were statistically significant differences. Item 1D [going to the mosque (Masjid) for five prayers (M)], was done mostly by males, and for this item the average for male patients was 3.1 while that for females was only 0.5 [t statistic  $p=0.178$  ( $p>0.05$ )], indicating a significant difference between male and female patients. For item 2D [doing prayers at home (F)], the average for female patients was 3.5 while that for males was 0.00. This was mostly done by females. The average for females was higher than that of males, with t statistics of  $p=0.001$  ( $p<0.05$ ), indicating a difference between male and female patients. However, for the majority of the dropped items, there was also no statistically significant difference between male and female patients. For example, 3A (cleaning at the toilet and covering yourself), the average value for male patients was 4.00 while that for females was 3.9. Even though male patients had a higher average than females, there was no statistically significant difference between males and females, with a t statistic of p value of 0.85 ( $>0.05$ ). This was true for all the other dropped items, as shown in the table. As for the majority of the dropped items, there was no statistically significant difference between male and female patients, except for the gender specific items (1D, 2D and 3D), and this is therefore further statistical justification for dropping the items.

#### ***3.2.7.4 Patterns of severity scores and scale scores***

The association between the severity and QoL was investigated as shown in **Table 3.13** by applying the cross tabulation between these two variables. This table shows that for 70% of the participants with severe aphasia, their QoL was either acceptable with 60% or not good with 10%, compared to 47.4% of the participants who had mild aphasia, with QoL either not good with 5.3% or acceptable with 42.1%; this also compares to 33.3% who had moderate aphasia with acceptable QoL. From this table, it can be said that as everything has been constant, there is a significant difference in the QoL for those whose severity was mild and moderate compared to those whose severity was severe.

Table 3-13 The association between severity and QoL

			Your life now				Total
			Not good	Acceptable	Good	Very good	
Severity	Mild	Count	1	8	6	4	19
		% within Severity	5.3%	42.1%	31.6%	21.1%	100.0%
	Moderate	Count	0	7	11	3	21
		% within Severity	0%	33.3%	52.4%	14.3%	100.0%
	Severe	Count	1	6	2	1	10
		% within Severity	10.0%	60.0%	20.0%	10.0%	100.0%
Total		Count	2	21	19	8	50
		% within Severity	4.0%	42.0%	38.0%	16.0%	100.0%

Also, by looking at the aphasia severity scores and the total score on the three domains scores, it can be said that there is a pattern between the severity scores and the scale scores, where the scores decrease as the severity increases as shown in **table 3-14**

Table 3-14 The association between severity and total score of the scale

Stroke severity	n	Physical	Communication	Social support	Total
Mild	20	27.3 (4.8)	26.6 (5.1)	28.9 (3.0)	82.7 (10.7)
Moderate	22	24.2 (8.4)	20.8 (6.8)	28.9 (3.3)	73.8 (14.6)
Severe	11	15.2 (7.2)	14.3 (6.6)	25.4 (4.2)	54.9 (15.1)
r (p one tailed)		-0.522 (<.001)	-0.603 (<.001)	-0.314 (.011)	-0.601 (<.001)

### 3.3 Chapter summary

This chapter described the stage of the main study where the final version of the questionnaire (VR3) was applied as a cross-sectional survey over two occasions. It introduced the 54 participants of Saudi PWA who completed the two occasions successfully, and also how this questionnaire was administered. After collecting data, the data was analysed and, to avoid bias, missing data were considered and four out of 54 subjects and 18 out of 58 items were considered as missing. The characteristics of the 50 participants indicated that this sample was a good representative group of Saudi PWA.

The psychometric properties of the questionnaire/ scale were evaluated and it was found to be valid and reliable tool for measuring QoL for Saudi PWA.

The underlying factors which may have an impact on QoL were investigated using the FA which was done using maximum rotation and applying the principal component matrix method. Its end result was a model of three factors composed of 21 items with seven items for each factor. This fulfils one of the research questions of this study, whilst also introducing a shorter version of the questionnaire/ scale which will be investigated in the next chapter.

The dropped 19 items from the 40-item questionnaire during the FA from different domains was investigated. For example, the religious duties and activities domain was presumed to have an impact on the QoL of Saudi PWA but interestingly it was dropped completely; the investigation revealed that the drop possibly occurred due to cross loading between other domains. Also, the correlations between these items do not necessarily mean they correlate with QoL. In addition, the dropped items could have been redistributed under another domain other than the one to which they belonged. Also, it suggests that these items might have remained if they had been asked in a form other than the one used. For other dropped items from other domains of the questionnaire, the investigation' results indicated that there were weak correlations between these items under the same domain in addition to their weak correlation with QoL, and this could explain their drop. Furthermore, the statistically significant investigation of the dropped items regarding gender differences suggests that, for the majority of the dropped items, there were no gender significant differences. This excludes gender specific items.



# Chapter 4: Developing a Short Version of the Questionnaire

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## 4.1 Introduction

Recently, many short scales have been developed for different purposes. These short scales were found to be appropriate by many investigators. Usually, the short versions were developed either as a replacement or as an alternative for their original questionnaire (Fayers & Machin, 2007). For this study to reach the goal of developing a measure of QoL, certain concerns were kept in mind while developing the measure. These concerns involved the nature and characteristics of the targeted population (PWA) and the presence of other problems, such as the communication abilities of the patients, their age group and how easily fatigued they are, which had encouraged the researcher to develop a shorter version in order to reduce the respondents' burden during the scale administration (Hilari et al., 2003). Therefore, to improve this measure and the questionnaire, it should be short yet able to cover and explore all the relevant issues of the study (Fayers & Machin, 2007). From the above, and based on the reasons and justifications mentioned, the researcher tried to develop a shorter version of the original (long) scale.

This chapter is outlined as follows: there is an explanation of how the short version of 21 items was developed from the last stage of the statistical analysis (see **Chapter three, Section 3.2.6.2**) in more detail in regard to the factors and items included. This is followed by an evaluation of the success of this short version as a representative of the original scale, and how it achieved these aims in terms of the statistical criteria of being a good representative. Next, there is an examination of this reduced version in terms of appropriateness and accessibility by applying a pilot study on 21 patients, then the pilot study is explained in terms of the participants involved, and the mode of administration of the questionnaire. In addition, the psychometric properties of this short scale are examined in terms of its internal consistency and test/re-test reliability and validity.

Furthermore, the potential predictors for QoL for Saudi PWA based on this application of the short version scale were investigated.

#### 4.2 How the short version (21-item) was developed

The final results of the FA of the original measure of 40 items, taking into consideration the seven items with the largest loadings on each factor, were a three factor model with 21 items. This could be used as a short and easy scale, yielding three scores, reflecting the most important factors of QoL presented in the original scale that was developed. This short scale and its 21 items are presented in **Table 4.1** below:

Table 4-1 The developed short version (21-item) of the questionnaire

S.No	Item	Statement of the item/question	Factor/Subscale	
		In the last two weeks, how easy has it been for you...	1	Mobility
1	Q4A	To walk by yourself		
2	Q5A	To balance when bending over or reaching		
3	Q6A	To climb the stairs		
4	Q13A	To be independent		
5	Q2A	To take a bath or a shower		
6	Q1A	To get dressed		
7	Q7C	To travel to other places		
		In the last two weeks, how easy has it been for you...	2	Communication
8	Q3B	To have your friends understand you when you talk		
9	Q8B	To tell stories about your life		
10	Q11B	To show others that you do not understand		
11	Q6B	To join others in a conversation		
12	Q4B	To speak clearly on the phone		
13	Q1B	To express your opinion		
14	Q7B	To find the words that you want to say		
		How do you see your relationship with ...	3	Social support & participation
15	Q3E	Your relatives		
16	Q2E	Your family members		
		Now, how do you feel about...		
17	Q10F	Your family's confidence in you		
18	Q9F	Being supported by the people around you		
19	Q5F	Keeping in touch with your friends		
20	Q6F	Being treated like a normal person		
21	Q11F	Your life now		

According to the new characteristics and features of these items/ questions involved in this short version, these three new factors/subscales were given new names expressing what they actually represented as subscales. The first factor/ subscale was associated with items which came mainly from the domain of the physical and daily life activities with six items, and one item from domain of the interests and leisure, which is related to physical movements required during travelling. This factor was therefore named *mobility* according to the general and common features of these items. The second factor/ subscale was associated only with items from the domain of communication. Thus, it was named *communication*. The third factor/ subscale was associated with items from the domain of social relationships and the domain of feelings and emotions, where it had most items from the domain of feelings and emotions, mostly related to the patient's exchange of feelings with the others toward his/her present status, and also related to the emotional support and participation that the patient might receive from his/her family members, friends and relatives. Thus, the features of this group of items reflect the support and the participation of the people surrounding the patient. Accordingly, this factor/ subscale was given the name, *social support and participation*. In this way, it can be said that the resulting three-factor model indicated that these three factors/ subscales and the domains should conceptually cover and reflect the most important factors for the QoL for Saudi patients with aphasia after stroke.

### **4.3 Evaluation of the short version: 21-item scale**

The short version of the questionnaire/ scale was tested and evaluated to assess its success as a representative for the original measure. By using the scores on both the 40- and 21-item scales from the same testing, the success of this shorter version scale was examined against four criteria, as follows:

The first criterion is that the total score of this 21-item test, should correlate strongly with the total score on the whole set of 40 items. To assess this, the correlation strength was examined for the total score of the 21 items of this short scale, with a total score of the whole set of 40 items of the original scale. The correlation of the total score on the 21-item scale with the 40-item was for test/ occasion one 0.990, for test/ occasion two 0.992 and for the mean 0.992. This indicates clearly that the subset of 21 items of the three factors covered almost all of the variance in these data sets. Consequently, this criterion is satisfied.

The second criterion is that there should be good test/re-test reliability for both the total score and the scores of tests from the three factors. The investigation of the test/re-test reliability for both the total score and the short test scores from the three factors, revealed that the test/re-test reliability was 0.996 for factor one, 0.992 for factor two, 0.950 for factor three and 0.994 for the total, which demonstrates excellent test/re-test reliability.

The third criterion is that the scores from the three subscales should be relatively independent from each other. The examination of the scores from the three subscales being relatively independent from each other revealed that subscales one and two correlated with 0.683 (this was for the total for tests one and two) and that they also both correlated with 0.683 for each one when taken individually. This was not large but is clearly significant; it accounted for 45% of the variance. Subscale one correlated 0.317 with subscale three, and subscale two correlated 0.369 with subscale three, sharing almost 15% less variance. These scores reflect the relative independency of these three subscales from each other.

Finally, the fourth criterion is that the scores from the three subscales should be strongly related to the corresponding factor score from the factor analysis of the full data set, but weakly related (or not at all) to the other factors. The investigation of this criterion revealed that the correlations were 0.914 for subscale one, 0.896 for subscale two and 0.915 for subscale three; these are considered strong correlations, while elsewhere the highest correlation is 0.398. This reveals that the scores from the three domains/ subscales were strongly related to the corresponding factor score from the factor analysis of the full data set but weakly related (or not at all) to the other factors, so this criterion is satisfied.

To conclude, from these findings it can be said that the short version of the questionnaire, which included only 21 items, covered virtually all of the variance in scores in the 40 items test. The three fairly independent subscales (dimensions) could be measured individually with high reliability. Furthermore, these statistical findings indicate the success of this short 21-item scale as a good representative for the 40-item scale.

#### **4.4 The effects of dropping items and subjects**

The analyses presented in chapter three were based on the 50 participants (out of 54) who gave ratings to 40 of the 54 items in the original scale. Subjects and items were eliminated to give a complete set with no missing data for the factor analysis. To investigate whether

the 21 items could account for the scores on each of the 54 items, multiple regression was used to predict the score for each item on the basis of the three component scores (i.e. the sums of the seven items selected for ‘mobility’, the seven for ‘communication’ and the seven for ‘social support and participation’). This analysis included, in every case, all available participants. None of these analyses include subject 44, who, on both occasions, would not answer Q8A. Beyond this, they include the other 53 subjects who all had scores for all 21 items. The results of this analysis, illustrated in **Table 4.2**, show clearly that once all the excluded items and subjects (apart from 1) were included, the reduced scale performed at least as well in accounting for the variance in the excluded items as the included items.

Table 4-2 The proportion of variance accounted for by multiple regression on the scores on each item: mean, standard deviation in parentheses

Assessment	Items included in the 21 item scale	Items excluded from the scale (n=33)
Assessment 1	0.707 (0.201)	0.737 (0.194)
Assessment 2	0.701 (0.198)	0.742 (0.194)
Mean of assessments 1 & 2	0.718 (0.195)	0.750 (0.189)

As a result, one should be confident that the reduced test did not introduce any bias in relation to the excluded items. These were excluded either because they did not have responses from all the 40 subjects included in the factor analysis, or because they were not among the seven most highly-loaded items for each of the three factors identified.

#### 4.5 Pilot study of the reduced version of the 21-item scale

After the statistical examination of the short version of 21-item scale, the short scale was piloted to check that it represented the original 54-item scale well. The pilot study ascertained the appropriateness of this shorter version for the population under study, Saudi PWA, in terms of acceptability and accessibility in spite of their communication difficulty. The investigation involved examining the internal consistency, test/re-test reliability and validity.

#### ***4.5.1 Participants involved in the pilot study of the 21-item scale***

To ensure the validity and reliability of the short scale, by investigating the difference of participants' scores on these items compared to their previous scores on the long scale, the scale was piloted on the subjects from the same group as the main study. This pilot study was performed three months after conducting the main study in order to avoid the subjects remembering their answers.

From the 50 patients who fully participated in the main study after clearing the data from missing subjects, 21 patients agreed to participate in the pilot of the short version of the questionnaire (21 items), which is incidentally the same number, for two occasions with 10-14 days in between. There was no need to redo the consent form as they had already signed it when they agreed to participate in the main study.

#### ***4.5.2 Mode of administration of the 21-item scale***

The researcher followed the same procedure that was used for the main study, which was explained earlier, by meeting the patients either alone or with their companion if the patient preferred, but without any interference from them, in a quiet room. Each session lasted between 10-15 minutes and was audio recorded to enable the responses to be checked when computing the data. This short scale was tested twice in order to examine its repeatability (reliability) and stability over time.

The study was explained again by the researcher to the participants and the instructions were presented to them to ensure their understanding of the nature of the task, which was similar to what they had already completed for the main study with the longer version of this questionnaire. The questions were read aloud and presented in the same written format used previously to overcome the reading and understanding difficulties or vision problems of the participants, arising from the variety of patients' characteristics and the severity of their aphasia. Thus, this 21-item questionnaire was presented using the same five-point Likert scale (1-5). This scale was presented in text and symbolic format in order to help those patients with reading difficulties. In regard to the communication problem, the researcher used all necessary means of support with the patient in order to ensure that the patient had understood the question well. The participants' responses were recorded on the response sheet.

### ***4.5.3 Data analysis of the 21-item scale application***

One of the goals of doing the pilot study and collecting the data of this short version scale was to investigate its validity and reliability, in order to be used as a representative or as an alternative for the longer assessment (40-item scale) of the QoL among the Saudi PWA due to stroke. The responses for both occasions were collected for each participant. Then, the recorded scores were transferred to SPSS software version 17.0. The data were re-checked after every third entry for all the data and all the participants on both occasions. All the patients fully completed the whole questionnaire (all questions/ items). Thus, no missing data were reported, the response rate was 100%, and all the patients proceeded to the next analysis stage.

### ***4.5.4 Descriptive analysis of the participants in the pilot study***

Patients' demographic and health-related information were collected from their medical records, and this data were also confirmed by the participant during the testing session. The demographic data of the 21 participants were examined in terms of age, gender, severity, marital status, post-time onset, education level, employment status, economic status and companion attendance, as shown in **Table 4.3** below.

Table 4-3 Characteristics of participants in the pilot study for the 21-item scale

Characteristics	N=21	Per cent
Age		
Average	47 years	
Range	23-64 years	
Gender		
Male	11	52
Female	10	48
Severity		
Mild	9	42.9
Moderate	10	47.6
Severe	2	9.5
Marital status		
Single	2	9.5
Married	16	76.2
Divorced	1	4.8
Widow	2	9.5
Post-time of onset		
Average	36 months	
Range	3-60 months	
Education level		
Illiterate	2	9.5
Able to read and write	3	14.3
Elementary education	3	14.3
Intermediate education	2	9.5
Undergraduate/university education	4	19
Postgraduate education	7	33.3
Employment status		
Employed	5	23
Unemployed	8	38
Retired	7	33.3
Other	1	4.8
Economic status		
Low	1	4.8
Average	13	61.9
High	7	33.3
Companion attendance		
With a companion	11	52
Without a companion	10	47.6

#### 4.5.5 Reliability of the 21-item scale

As mentioned before, reliability indicates whether the measure/ scale (short version) that was developed for the assessment of QoL was consistent. The reliability of the short version (21-item) was measured by using test/re-test reliability and internal consistency as in the main study.

#### 4.5.5.1 Internal consistency

The reliability of the measure was determined for the 21 patients by measuring the internal consistency of variables involved. The internal consistency of this short version (21-item) was tested with Cronbach Alpha ( $\alpha$ ) and resulted in a very good internal consistency where  $\alpha = 0.896$ , according to Fayer and Machin's (2007) criteria.

#### 4.5.5.2 Test/re-test reliability

Test/re-test reliability is used to check the correlation of the scores for the same individual in a scale on two separate occasions. The Pearson correlation coefficient was used here to measure the test/re-test reliability of this scale. The test/re-test reliability for this short version scale was very good, with an overall correlation coefficient of ( $r$ ) 0.992.

The test scores on the two occasions for the complete test and each of the three sub-scales are shown in **Table 4.4**, together with the test/re-test reliability (expressed as Pearson's correlation ( $r$ )) and the 95% confidence interval of an individual score. As a result, a change of two in the total score for any of the three subscales will be significant, and a change of 3.5 or more in the total.

Table 4-4 Test/re-test reliability scores for both complete and short scale on the two occasions

Scale	Test 1 Mean (sd)	Test 2 Mean (sd)	Test/re-test ( r)	95% CI for an individual score
Mobility	26.9 (7.2)	26.6 (7.5)	0.995	±1.60
Communication	23.7 (6.3)	23.5 (6.6)	0.994	±1.51
Participation	28.4 (3.0)	28.6 (3.0)	0.958	±1.78
Total	79.0 (12.0)	78.7 (12.5)	0.992	±3.29

From these reliability results, it can be said that the 21-item version is reliable with Cronbach alpha ( $\alpha$ ) of 0.896. By comparing this value with the Cronbach alpha of the longer version, which is 0.97, it can be said that there was no great difference. One can be confident in concluding that the reliability of the two versions is similar, which supports the developed shorter version.

#### **4.5.6 Validity of the 21-item scale**

To maintain the validity of the developed questionnaire in its short version and in order to increase its content validity, the pilot study for the 21-item questionnaire/ scale was performed. The researcher took all reasonable precautions to ensure that the questionnaire was accessible and acceptable for the patients, as in the main study. In addition, the researcher helped the patients who had communication problems to respond to questions, which were difficult for them to understand, by providing information using all necessary means.

##### **4.5.6.1 Participants' responses to the scoring of the scale**

In regard to the responses to the scoring sheet using the VAS, five out of the 21 patients needed more help, and so a gesture was used (pointing to the stars on the VAS). Two of these patients had severe aphasia and three had moderate aphasia. Three patients had reading difficulties (one with severe and two with moderate aphasia) and the other two did not read. Three of these five patients were wearing glasses (one had severe aphasia and two moderate aphasia). Therefore, the researcher repeatedly had to provide an explanation about the scoring sheet for them. For the rest of the 16 participants, (the nine with mild and the seven with moderate aphasia) the scoring sheet was easy to complete. In general, it can be said that this method was effective and easy to use and appeared to provide meaningful value for the relative preferences for the patients.

#### **4.6 The potential demographic and health-related predictors of QoL for Saudi PWA, as measured by the 21-item questionnaire**

One of the aims of this study is to explore the potential demographic and health-related predictors of QoL for Saudi PWA. To achieve this aim, after the results of evaluating the psychometric properties of this short version were obtained, and based on the literature review for this study, the potential predictors of QoL were investigated. These potential predictors are demographic variables, which were: age, gender, educational level, employment status, companion presence and socio-economic status and health-related variables which were severity of the aphasia, and time post-onset of stroke.

Pearson correlation were used in order to show that the total test score relates to subject variables as the researcher predicted. Simultaneous regression was not preferable here because it determines whether the independent variables have an independent effect on

the QoL. The researcher had some expectations in regard to whether these variables would have significant effects on QoL, for example it is expected that patients with more severe aphasia would have a poorer test score, as would patients with lower socio-economic status (SES), with a companion, a lower level of education and older age patients.

This analysis was applied to the data from the main study in chapter three by taking each variable individually as a predictor of the overall test score on the 21 items, where the one-tailed test was used because of the researcher's specific predictions about this group of variables. The results of the analysis show that there are clearly significant effects in the predicted direction for age, severity, socio-economic status (SES), companion presence and education, which supports the researcher's predictions. On the other hand, gender, post-onset time (stroke year) and employment variables seem to have no significant effect on QoL.

In relation to demographic factors, age was found to be significantly negatively correlated with the mean test of the 21 items ( $r = -.39$ ,  $p < .05$ ,  $0.00$ ) with increasing age resulting in poorer QoL scores. For gender, no significant effect on QoL was found. There was a weak correlation between gender and QoL ( $r = .029$ )<sup>7</sup>, and this correlation also was not significant ( $p > .05$ ,  $.08$ ). For the socio-economic status (SES), the scores of the three SES groups (low, middle and high income) revealed that the results were significant ( $r = .28$ ,  $p < .05$ ,  $0.01$ ), indicating that QoL is positively correlated with (SES) and, therefore, the higher the income, the better the QoL. The companion effect, companion presence, was found to be significantly positively associated with QoL. The QoL test scores ( $r = .41$ ,  $p < .05$ ,  $0.00$ ) indicate that poorer QoL was associated with the companion presence. In regard to educational level, the correlations of the mean for the six groups of education levels were ( $r = .43$ ,  $p < .05$ ,  $0.00$ ). The results were significant and indicated that a positive association was found, and so an increase in education level was correlated with better QoL. For employment status, the scores of the mean for QoL test were not significantly correlated with its four status levels ( $r = -.10$ ,  $p > .05$ ,  $0.21$ ).

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<sup>7</sup> This correlation coefficient is equivalent to a two-sample t-test

To explore whether stroke severity had an effect on QoL in Saudi PWA, QoL was correlated with degree of severity (mild, moderate and severe). The severity of aphasia was significantly negatively correlated with the mean test scores, with ( $r = -.60$ ,  $p = <.05$ ,  $0.00$ ). This indicates that the greater severity degree of aphasia, the poorer the QoL.

The scores of the mean of the time post-onset (stroke year) were found to be not significantly correlated with scores of the QoL, with ( $r = -.15$ ,  $p >.05$ ,  $0.13$ ) for all groups of time post-onset. It can therefore be said that for the stroke and health variables only the severity variable was significantly associated with the QoL of the participants.

In summary, the demographic variables that were significantly associated with QoL are: age, where increased age is associated with poorer QoL; socio-economic status (SES), where the higher QoL is associated positively with higher socio-economic status; educational level, where the higher level of education is associated with a better QoL, and the absence of a companion with the patient, which is positively associated with a better QoL. Gender and employment status were not found to be significant in relation to QoL. On the other hand, the severity of aphasia is the only health-related variable that was associated with QoL, where greater severity is associated with poorer QoL. However, the post-onset time variable is not associated with QoL. These results will be discussed in more detail in the following discussion chapter.

#### 4.7 Chapter summary

In this chapter, the resulting 21-item scale reflected the most important factors of QoL for Saudi PWA after stroke, within three factors/ subscales with seven items, which expressed *mobility*, *communication* and *social support and participation*. It was evaluated in terms of statistical criteria and found to be representative of the original scale. The statistical evaluation of the 21-item scale in relation to the 40-item scale showed that the total score of this short test correlated strongly with the total score on the whole set of 40 items. Moreover, it had excellent test/re-test reliability; the scores from the three subscales were found to be relatively independent from each other and the scores from the three subscales were strongly related to the corresponding factor scores from the factor analysis of the full data set, but weakly related (or not at all) to the other factors. Also,

the results of multiple regression analysis indicated that this short scale did not introduce any bias in relation to the excluded/ dropped items.

This 21-item scale was piloted on 21 patients on two occasions and found to be valid and reliable. Also, it was found to be appropriate, acceptable and accessible to Saudi PWA. From these results, it can be said that the aim of this study for developing a valid, reliable, socially acceptable and culturally appropriate scale of QoL for Saudi PWA was achieved.

As an aim of this study, the potential predictors of demographic and health-related factors for QoL of Saudi PWA were investigated using this short scale. The results of this investigation revealed that there are clearly significant effects in the predicted direction for age, severity of aphasia, socio-economic status, companion presence and educational level on the QoL for Saudi PWA, and this supports the predictions of this study. However, gender, post-onset time and employment status variables seemed to have no significant effect on their QoL.

## Chapter 5: Discussion and Conclusions

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This study explored the factors that affect QoL for Saudi patients with aphasia after stroke, including cultural and religious issues specific to Saudi society. Further, the study aimed to develop a QoL assessment tool for these patients, to examine its psychometric properties; the validity, reliability, accessibility and acceptability; to explore the relationships between domains, and to investigate the relationships between QoL and other health and demographic predictors.

There were three phases in this study. Initially, the questionnaire was developed in three stages: first, there was the review of the literature and development of a preliminary version of the questionnaire and cross-cultural adaptation process; second, a triangulation process was conducted that involved gathering the views of key professionals, lay people and PWA; and third, there was the development of a revised version of the questionnaire, based on the themes derived from the outcome of the thematic analysis of the views gathered during the triangulation process of the three sources. The questionnaire was further modified and then piloted with 11 PWA. The third and final version of the questionnaire was used in the main study.

The second phase of the study was the application of this final version of the questionnaire to 54 PWA. From the data gathered, the validity and reliability of this questionnaire were examined, and the data were analysed to explore and identify the underlying factors/variables that would explain patterns of correlations among these responses, and reveal the number of factors and variables that belonged to specific factors. This was achieved using factor analysis. From this, a shorter version of the questionnaire was developed. The third phase of the study involved exploring the psychometric characteristics of the short questionnaire and examining its validity and reliability with 21 PWA.

This chapter will now discuss the findings of these three phases in relation to the research aims.

## 5.1 Factors affecting QoL in Saudi PWA

The first research question aimed to explore factors that affect QoL for Saudi PWA after stroke, including Saudi-specific cultural and religious issues. This exploration was carried out using both qualitative and quantitative methods. During the first stage of this study when qualitative methods were applied, the findings from the thematic analysis of the interviews about the QoL of Saudi PWA and in the final stage of developing the questionnaire, demonstrated that communication, physical difficulty, social and family relationships, religious duties, and emotions and feelings were relevant themes. Based on the following pilot study of the developed questionnaire and face-to-face semi-structured interviews, the identified themes were: physical and daily life activities, communication, interests and leisure, religious activities, social and family relationships, and feelings and emotions.

The results of the factor analysis of the developed questionnaire and the development of the short version questionnaire indicated that, the main factors that affected QoL in these Saudi PWA after stroke were mobility, communication and social support and participation. It can therefore be said that the results of this quantitative phase agreed with the earlier results of the qualitative methods phase, in that physical and daily life activities, communication and social and family relationships were important QoL factors for Saudi PWA.

The results obtained in this study agree with the literature, as many researchers have identified physical and daily life activities as being among the main predictors of HRQoL post-stroke (Ahlsjö et al., 1984; Aström et al., 1992; Carod-Artal et al., 2000; Ebrahim et al., 1986; Jonkman et al., 1998; King, 1996; Kwa et al., 1996; Niemi et al., 1988; Wilkinson et al., 1997). These wider findings can be applied to this study as the aphasia of the sample patients also occurred as a result of stroke. Communication was found by this study to be a major factor in QoL for Saudi PWA, in that higher communication disability was associated with poorer QoL. This finding is similar to the results of a study by Kwa et al. (1996), in which severity of aphasia was found to be a significant predictor of QoL. In contrast, Ross and Wertz (2003) found no significant association between severity of language-based disability and QoL with mild to moderate aphasia, which may indicate that the experience of living with aphasia may be most affected by aspects other than severity. Many studies have found that social support and relationships are key

factors in the QoL of PWA who live successfully with it (Brown, Worrall, Davidson, & Howe, 2010; Cruice et al., 2010).

However, in this stage it should be noted that, in spite of the importance of religion in Saudi culture, all items from the religious factor were completely dropped. The remaining items of the other factors (interest and leisure, feelings and emotions) were re-distributed to form the social support and participation factor, to be added to the other two factors of mobility and communication.

## **5.2 Developing an assessment tool for QoL for Saudi PWA**

The second research question aimed to develop an assessment tool for QoL for Saudi PWA after stroke, examining its validity and reliability and exploring the health and demographic predictors affecting their QoL.

### **5.2.1 *The psychometric evaluation of the questionnaire***

This evaluation involved testing accessibility and acceptability, and examining reliability and construct validity. To test the accessibility and acceptability of the questionnaire, the response rate and percentage of missing data were calculated. For the reliability testing, the internal consistency and test/re-test reliability of the questionnaire were assessed.

One possible limitation of the psychometric evaluation of the questionnaire/ scale is the sample size of this study. However, under some circumstances, a sample size of 50 may be adequate if there is a strong correlation and a few distinct factors, as long as there are notably more cases than factors (Fidell & Tabachnick, 2001; Sapnas & Zeller, 2002). Therefore, the size of this study is adequate for the psychometric analysis, with 54 cases for three factors. The main findings are discussed below in terms of the properties tested.

- **Accessibility**

The questionnaire pilot study indicated that it was highly accessible to patients with any degree of aphasia. Accessibility was judged by taking the views of the PWA into account. All participants found the questionnaire to be straightforward and no difficulties were reported, as indicated earlier in **Chapter two, Section 2.3.3.6**.

- **Acceptability**

In the pilot study, PWA found the questionnaire extremely acceptable. Items regarding clothing within the physical and daily life activities domain needed to be more specific as to the type and gender, and so the administration of these items was modified to become suitable for application in the main study according to the participants' feedback, as indicated earlier in **Table 2.7**.

- **Reliability**

According to the criteria used in this study for reliability, the questionnaire had very good test/re-test reliability, with a Pearson correlation coefficient of .997. For the short version questionnaire, the overall test/re-test reliability was 0.992.

- **Validity**

In terms of content validity, ten items were added to different domains in the final stage of developing the questionnaire, based on the semi-structured interview within the pilot study. No further items were added after this stage and the scale/ questionnaire was thought to have good overall content validity, where the items are sensible and reflect the intended domains of interest. The triangulation process was used to collect views from three different groups: professionals, non-professional and PWA. This supported the good external validity of this questionnaire.

The construct validity of the measure was tested, and from the FA it was confirmed that this scale measures what it was designed to measure to a good degree. Therefore, conceptually, the factor model structure was developed from all 58 items. The short version derived through FA had a stable, conceptual three factor structure with good construct validity of 67% variance. The construct validity within the scale was evaluated through the inspection of the inter-correlations between the scale domains and the domain items themselves, and by examining the theoretical relationship of the items to each other and to the developed scale using FA. Therefore, FA was used to test both the structure of the questionnaire as holding six domains and these domains' correlations, and to develop the best factor model to describe the data in a short questionnaire with three factors of 21 items.

In conclusion, it can be said that as a result of exploring the factors affecting QoL in Saudi PWA the main factors identified were mobility, communication and social participation and support, which were confirmed by FA and presented in the short version of the questionnaire. This short version of the questionnaire with 21 items was developed from the full version. It captured each of these three factors/domains resulting from the FA, taking the seven questions/items that loaded best on each of the three factors. The first domain was *mobility*, which is associated with items related to physical and daily life activities and movements. The second domain was *communication*, which is associated with items related to communication modalities. The third domain was *social support and participation*, which is associated with items related to social relationships and feelings and emotions within family, friends and relatives' support and participation. Although the longer version had more items, the short version is a more stable factor model, as indicated by the FA.

In summary, the development and psychometric evaluation of the questionnaire (long version) showed that this questionnaire was an accessible, acceptable, reliable and valid measure for the assessment of Saudi PWA. On the other hand, the short version indicated that it was a good representative of the original questionnaire. The short version of the scale with 21 questions (developed on the basis of factor analysis of the original dataset) was also shown to be valid and reliable.

### **5.2.2 Potential predictors of QoL for Saudi PWA**

In the literature, different predictors of QoL for PWA post-stroke have been identified, but there are challenges in considering this evidence in relation to the population under study, mainly the cultural and social differences for Saudi PWA. Therefore, within the current study demographic- and health-related variables were examined as possible predictors of QoL. The demographic-related potential predictors/variables are the following: age, gender, socio-economic status (SES), marital status, employment status, educational level and company attendance. The health-related potential predictors/variables are the severity of the aphasia, and time post-onset of stroke.

Using results from the 21-item questionnaire, the scores of the correlation of QoL and health-related predictors revealed that only one health variable, the severity of aphasia and the following demographic variables (age, socio-economic status (SES), companion presence and educational level) were significant predictors of QoL for these participants.

Other demographic factors in this study, namely gender, marital status, employment status and the year of the stroke (time post-onset) as a health factor, were not significantly associated with QoL.

In regard to the health and demographic variables, the findings of this study can be explained as follows. For severity, the results showed that the severity of aphasia is significantly associated with QoL. Previous research such as that by Hilari and Byng (2009) suggest that overall HRQoL in people with severe aphasia is severely affected; for aspects of QoL related to communication and physical functioning, they concluded that the QoL of people with severe aphasia is significantly worse than that of patients who have a moderate or mild degree of aphasia. However, these findings should be taken cautiously because in their study the researchers used proxies for the severe PWA, while those with moderate to mild forms had self-reported data. The literature suggests that there is a relationship between the level of agreement between the patients and their proxies and the severity of disability, as suggested by Ross and Wertz (2003), who noted that proxy raters tend to report more HRQL problems than the patients themselves. In this way, one can expect that proxy respondents would overestimate the ability of people with severe aphasia (Sneeuw, Aaronson, deHaan, & Limburg, 1997). Furthermore, Kwa et al. (1996) have findings which suggest that the severity of aphasia is associated with reduced HRQoL.

In this study, age was found to be significantly negatively correlated with QoL, where the poorer QoL scores were associated with increasing age. However, the relationship of age and QoL is not universally reported. So, some studies considered the impact of age on QoL as a significant predictor, such as a study by Hilari et al. (2003), indicated that increased age is significantly correlated with poorer HRQoL for PWA after stroke. The literature also notes that older age groups are associated with reduced HRQoL after stroke (Aström et al., 1992; De Haan et al., 1995). Niemi et al. (1988) found that HRQoL in older patients was more severely affected than in younger ones. On the other hand, other studies, in relation to HRQoL after stroke do not show this, as indicated by Ahlsjö et al. (1984) and Ebrahim et al. (1986), who found no effect of age. However, Wyller et al. (1998) found that better well-being is associated with older age. These differences in findings may reflect the way HRQoL was differently conceptualized and measured in these studies. Thus, it can be concluded that the result of the current study on Saudi PWA agreed with most of the findings in the literature about QoL after stroke, in that poor QoL

is associated with older age. However, this finding should be considered with caution as only 2.8% of the Saudi population are aged 65 or more, and stroke in younger age groups is common in the Saudi environment (Awada & Rajeh, 1999).

Three remaining aspects of note are socio-economic status (SES), education level, and presences of the companion in the patient's life. For SES, this study found it to be positively associated with QoL, and this finding agrees with those of King (1996), within a stroke population, who found that better HRQoL is associated with higher SES. However, another study found no impact of SES on HRQoL after stroke (Ahlsjö et al., 1984). In this study, one possible interpretation of this finding is that high income and financial support were thought to help Saudi PWA to have more opportunities to make their lives easier and add more to their QoL, for example having access to better treatment and rehabilitation either in the country or abroad, and having housemaids, drivers and private nurses, may have led to the positive association between SES and higher QoL. Again, this result should be treated with caution as there is no official classification of socio-economic status in the Saudi population and the patients' responses for the classification in this study were based on the patients' personal judgments on their socio-economic status.

In this study, a higher educational level was associated with higher scores on the QoL questionnaire. This concurs with the literature in that a higher education level was associated with increased HRQoL (Neau et al., 1998). One possible interpretation for this result is that for most of the Saudi population to have a higher level of education means there is a chance to have a decent job with a good salary, which means more independence, having a permanent income and a pension after retirement.

In regard to the relationship between the presence of the patients' companion and QoL, it should be noted that for Saudi PWA, the presence of the companion means the dependency on them in many ways such as communication and daily life physical activities and at different places such as home and outdoors. The results of this study indicate that better QoL is associated with less dependence on the companion. This result was also shown in the participants' responses during the semi-structured interviews earlier. This finding is similar to the reported result of the study of Ross & Wertz (2003), which found that the QoL for PWA is affected negatively when the patient becomes more dependent on others.

Also, Aström et al. (1992) reported that daily life activity dependence is associated with low life satisfaction post-stroke, in addition to the fact that increased dependency, a reduced social network and reduced leisure are related to poor life satisfaction. Furthermore, this result is supported by the findings obtained in two studies by Herrmann and Wallesch (1989;1990) from patients, proxies and clinicians, which suggest that loss of independence, the inability to work and social isolation have a severe impact on QoL. From this it can be concluded that dependence on others in the life of Saudi PWA, such as physical and social activities, is one of the issues that should be looked at when measuring QoL for these patients.

In conclusion, this study found that mobility, communication and social support and participant were clear factors affecting QoL for Saudi PWA after stroke. However, the religious factor was hypothesised to be important in the Saudi culture and therefore in QoL, but it did not emerge. Also, severity of aphasia, age, SES, companion presence and educational level were found to be the only health- and demographic-related variables/predictors associated with QoL for these patients. Furthermore, the developed assessment tool for QoL for Saudi PWA was examined and found to be valid and reliable measure.

### **5.3 The role of religion in QoL**

Evidence has demonstrated that religion can be associated with life satisfaction and QoL, but this has not been investigated before in PWA in a dominant Muslim culture like Saudi Arabia. This thesis therefore sought to investigate the impact of religion on QoL because Islam is a key part of Saudi culture and cannot be ignored when providing health care and rehabilitation programmes for patients.

One of the interesting findings of this study was the dropping of the religious factor because it was not associated with QoL for Saudi PWA, despite the fact that religion was hypothesised to play a major role in relation to QoL for Saudi PWA. According to Holt, Schulz, and Wynn (2007), the association between religious faith and health has been found to be significant in many studies; however, the psychological basis for this association remains unclear, so understanding the effect of the religious role on the recovery and rehabilitation process is important in Arabian and Islamic culture, where it is a major part of everyday life (Rashidi & Rajaram, 2001).

Matthews et al. (1998) associated religious commitment with being a community of faith and sharing practices and beliefs, while Giaquinto et al. (2007) and Williams and Sternthal (2007) viewed religious commitment as shared doctrinal beliefs and participation in certain behaviours. In relation to QoL, Zullig, Ward, and Horn (2006) note that several studies have suggested how religiosity and spirituality can have a significant effect on measures of QoL.

Greene and Yoon (2004), who used a large quantity of data from the Euro Barometer Survey, found that an individual's life satisfaction is positively associated with measures of strong religious attachment, in the sense of being willing to commit to attending a religious service frequently. In addition, Maselko and Kubzansky (2006) found that there was a significant association between weekly religious activity and better health and well-being. These findings should be considered with caution as they were completed in Western countries where the dominant culture and religion are different. The literature reveals a significant gap in the available knowledge on the association between religion and QoL or life satisfaction in Muslim cultures, even though this is arguably very important.

The domain of spiritual religious and personal beliefs (SRPB) was developed by WHO within the WHOQoL-SRPB, which is the World Health Organisation Spirituality, Religion and Personal Beliefs questionnaire (WHOQoL Group, 2006). It included eight aspects (connectedness, spirituality, faith, wholeness, meaning and purpose, awe and wonder, spiritual strength, inner peace and hope and optimism) (Skevington, Gunson, & O'Connell, 2012). However, no aspect involving any religious duties or activities was assessed, as it focused on beliefs rather than actions.

Therefore, the religious aspect of the participants in relation to the current study was investigated through the dimension of religious duties and activities, and not through examining beliefs. However, the literature relating to religion and coping with stroke and aphasia is limited. Lev (1992) suggested that prayer can facilitate coping and aid in the reduction of stress, yet this claim is not specific to patients with stroke.

Within the current study, the religious items did not emerge as a theme/domain. Whilst this appears at odds with the evidence, in fact there are several factors which must be considered. For example, from this literature, it should be noted that these studies investigated different aspects of religion, such as religiosity, spirituality, and attendance

at religious services. Others investigated different impacts on the person's QoL, such as subject well-being, life satisfaction, and happiness, as well as how religion can influence the person's ability to cope with a disorder. In addition, these studies were carried out in different cultures and on different religions. Therefore, because of such factors, the result of dropping the religious items in this study cannot be said to contradict with the literature.

In this study, the statistical explanation for dropping these items was mentioned previously (see **Chapter three, Section 3.2.7**). However, possible reasons which may explain this drop relate to the unique characteristics of this culture and religion. The main possible reasons for the lack of association of religious items with QoL are that an inappropriate tool was being used to measure religious impact through religious duties and activities, and that the religious beliefs can be linked to surrender and acceptance. These issues are presented in the following section.

### ***5.3.1 An inappropriate tool for measuring religious impact***

In spite of the religious questions having no higher or lower rating than others, this may indicate a potential bias towards giving a socially desirable answer as a possible result of using a face-to-face interview-based questionnaire, as indicated by (Presser and Stinson (1998)). It is possible that the participants in this study were conscious of being perceived or judged as insufficiently religious and perhaps provided the socially accepted answers to the questions asked. This issue may shed some light on possible difficulties in determining the influence of religion in some cultures, such as the Saudi culture, where people are expected to have a strong commitment to Islamic religion at least in the public eye. Indeed, this issue may be deeper than social desirability as there may be a strong belief that the person should be religious and their faith unquestionable. Thus, the patient may not feel comfortable revealing any doubt, even if they were engaged in a more probing interview, in order to avoid any criticism of their religion.

### ***5.3.2 Religious beliefs regarding surrender and acceptance***

In a culture like the Saudi culture, where pure religion is perceived as surrendering to God's will, the issue of acceptance could be responsible for the dropping of the religious items. From the results obtained, the religious questions correlated almost as well as the other questions with the total score, where many subjects did not answer the religious questions which are gender specific. Also, the participants did not rate themselves higher

for religious questions as a reflection of their faith and complete surrender to God. This result could be explained by a possible difference between belief and action. Despite the general and public trust in God, Saudi PWA, due to their different daily challenges, could still privately rate their QoL as being poorer.

In this aspect it can be concluded that in spite of the important role of religion in the Muslim's life, the main possible explanation for the dropping of the religious factor is the inappropriate tool used to measure the religious impact and the Muslim's acceptance and trust in God's will, which should be considered carefully when measuring religious impact on QoL in such a Muslim population.

#### **5.4 Contribution of the study**

This study has developed an assessment of QoL for Saudi PWA. This assessment tool was developed systematically on the basis of information drawn together from the main stakeholders involved, the views of 11 Saudi patients with aphasia, nine Saudi speech language pathologists (SLPs), and 66 ordinary/lay Saudi people through the triangulation process. The development procedure involved a cross-cultural adaptation for the suggested items/questions of the drafted questionnaire. It also included a pilot study of the draft questions with a semi-structured interview with the PWA who had the same characteristics of the targeted population. Thematic analysis was carried out during different stages of developing the questionnaire. This resulted in a questionnaire probing six domains with 58 questions. This questionnaire was used with 54 PWA on two occasions. The questionnaire showed excellent test/re-test reliability over a period spanning 14 days. Factor analysis of these results suggested that the test could be successfully reduced to 21 questions that probed three domains equally: mobility, communication and social support and participation. Both the original set of 54 items and the reduced set of 21 items showed excellent test/re-test reliability and internal consistency. In the absence of any external 'gold standard' assessment of QoL for people with aphasia in Saudi Arabia, this investigation sought external validation by examining the results of the full and reduced assessment in relation to factors that previous findings show are related to QoL after stroke.

The results of this study agreed with what is found in the literature in regard to the possible factors, which are mobility, communication and social support and association, and health and demographic predictors. These are severity of aphasia, age, socio-economic status

(SES), companion presence and educational level, all of which are associated with QoL post-stroke, and which reflect the good validity of this measure.

There are some factors that add strength to this development process and to the study. For example, there was a clear justification for the weighting of domains and items involved in this process. This development was data driven through all stages. The success of the short version (21 items) as a representative of the original measure (40 items) was tested against certain criteria, as described in the previous chapter in **Section 4.3**, and the findings showed the success of this short scale as a good representative for the original scale.

Additionally, in this study the sample used in developing this assessment tool was a representative sample, which included a variety of degrees of aphasia and no use of a proxy, where a self-administered interview questionnaire. Also, the effects of dropping some of the items were examined to investigate whether the short version items could account for the scores of all the items involved. Therefore, the reduced scale did not introduce any bias in relation to the excluded items. Furthermore, potentially statistically significant differences between gender on the dropped items and on QoL were examined, but the results showed that there was no statistically significant difference between male and female patients, except for the gender specific items.

Other previous attempts include the Stroke and Aphasia Quality of Life Scale (SAQoL) (Hilari, 2002). However, the development of this measure was different from the current study's assessment tool. The SAQoL, which was developed from an existing measure called the Stroke-Specific Quality of Life Scale (SS-QoL) (Williams, Weinberger, Harris, Clark, & Biller, 1999), adds just three questions intended to probe language impairment. These added items focus on difficulties with understanding speech, and the impact of language problems on family and social life. The development of an aphasia adapted version of SS-QoL was basically only a modification of items in this instrument, which was originally designed for patients with stroke and not aphasia, without actually trying to explore the domains that might be affected by aphasia. Therefore, there was no clear justification for the weighting of domains and the items involved, and there is no strong evidence whether it adequately covers all aspects of QoL for PWA or not. It was a data driven study, but it was applied to patients with mild and moderate aphasia and proxy respondents were used for patients with severe aphasia.

From the above, it can be concluded that the current assessment is a good measure for QoL of PWA because of its development procedure and the stages involved, and its high reliability and validity, which can be considered a new contribution to the field of assessment of QoL for PWA post-stroke.

### **5.5 Research significance**

From a theoretical perspective, this study adds new knowledge to the field of QoL and aphasia as the majority of the studies reported in the literature were carried out in Western countries. No previous study appears to have investigated the factors associated with QoL for PWA post-stroke in a predominantly Muslim population. This study provides insight into Saudi culture in relation to aphasia. Social life in Saudi Arabia differs from that in Western countries in many ways. These include: the predominance of the Islamic religion, extended family life structure, views of health, illness and treatment, and social interaction, in addition to the prevalence of servants (house mates and drivers) for the majority of Saudi families; all of these issues have a real impact on perceived QoL. As a consequence, results from Western populations cannot be uncritically generalized to an Arab population.

From a practical perspective, the development of the assessment tool of QoL for Saudi PWA is considered a new addition to the field, as no previous measure has been developed for this group of patients in any similar culture. The results of this study provide an important base for Saudi healthcare services, speech therapy practice, and future research, which should be very useful for policy makers in Saudi Arabia.

This study makes a clear contribution to our knowledge base about assessing QoL for PWA in Saudi Arabia. In terms of developing this work further, suggestions for further research are as follows:

- (i) The questionnaire and its psychometric properties

The psychometric properties of this questionnaire/ scale can be evaluated by applying it to a broader population. Further psychometric evaluation of this questionnaire/ scale for a larger sample could allow standard scores to be developed that would allow comparison with other standardised QoL scales and with the results of other studies in the field of QoL. Furthermore, it should incorporate responsiveness to change within longitudinal studies, where the scale is able to detect clinically significant change over time. Indeed,

as Deyo, Diehr, and Patrick (1991) indicated, a health outcome measure must be able to detect small but clinically important differences in outcome which are considered important by the professionals and patients; thus, further testing is needed in the evaluation of using such a scale in routine clinical practice.

(ii) The clinical implications of the questionnaire

The questionnaire revealed that it is easily accessible and acceptable, and moreover reliable and valid as a scale. In regard to clinical usage, further research is needed to evaluate this scale as a measure for the clinical decision making for a patient's individual intervention and treatment plan, using the outcome of this scale/ measure.

(iii) Broader research perspective

This study may provide useful information on the appropriateness, practicality and responsiveness of the questionnaire/ scale as an outcome measure for QoL for Saudi PWA, which helps generate further ideas of how to assess the QoL in Saudi PWA.

From a broader perspective, further research on QoL might also look at proxy and self-report agreements in Saudi PWA having different degrees of severity of aphasia; this could help, for example, to explore the areas and direction in which disagreement is found between the PWA and their proxies, and what justifications can be provided.

Research on the interpretation of QoL results could be used to explore different stakeholders' perspectives; this was not applied more with this questionnaire/ scale, due to the limited literature in this field. Extended research into the QoL for Saudi PWA, by using such a scale, could be used alongside other commonly used measures in aphasia to explore how to calibrate the meaning of changes in this scale, in relation to other measures, in order to obtain meaningful information for professionals and the patients themselves.

(iv) The religious and cultural perspectives for Saudi PWA

Further research on a larger scale could involve investigating the same issues, in particular the significant role of religion in QoL but with the inclusion of people with and without aphasia post-stroke. This would allow for a better understanding of the impact of aphasia as opposed to the impact of stroke on their QoL and exploring the similarities and

differences found. Also, these issues could be investigated with non-Saudi Muslim patients from other countries, such as Gulf countries.

The issue of cultural characteristics specific to Saudi PWA that may have an impact on the intervention and rehabilitation programmes in clinical settings should be considered for future research. This would include strong family involvement in the PWA's life, dependence on others, religious beliefs and social stigma, and isolation, which should be considered in such programmes to avoid any possible clashes that may be found from both the PWA and their families. Such issues should be fully understood by the professionals, family members and the patients themselves, and the therapy goals should be clear for all parties. Therefore, the goal settings should be relevant to the patient's wishes and family expectations. Also, another issue worth investigation is the educational awareness programmes at the national level which are needed in regard to aphasia and stroke, and their consequences for the patient's QoL and the services that can be provided for them.

# Appendices

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## **Appendix A: The adaptation of the selected questions from the existing measures**

**For the SAQoL-39:** How much trouble did you have: SC4. getting dressed? SC5. taking a bath or shower? M4. keeping balance when bending over or reaching? M6. climbing stairs? M9. getting out of a chair? UE1. writing or typing, i.e. using hands to write or type? UE4. doing buttons? UE5. doing a zip? L3. speaking clearly enough to use the phone? L5. getting other people to understand you? L6. finding the words you wanted to say?

To be modified into: to get dressed by yourself? Taking a bath or a shower by yourself? Keeping your balance when bending or reaching? Climbing stairs by yourself? To stand to get out of the chair? To write or type? Doing buttons? To do a zip by yourself? To speak clearly on the phone? Getting other people understand you? To find the words you want to say directly?

**For the QCL:** 6. I stay in touch with family and friends. → You feel that you are keeping in touch with friends and colleagues; 8. I follow news, sport and stories on TV/movies. → Follow news and sport on TV and 15. I get out of the house and do things. → Get out of the house and do things such as shopping, sport, social gathering, visiting family members or friends.

**For COAST:** How could/ can you: 5. Join in a conversation with a group of people. → Join in a conversation with a group of people (no change); 7. understand simple spoken information → Understands simple/ short sentences or information and 8. Show that you do not understand? → Showing that you do not understand something.

**Appendix B: Survey questions for the professionals (Saudi SLPs) and response summary**

Questions statement	Percentage of responses %					Inclusion	
	1	2	3	4	5		
To get dressed by him/herself?			10	40	50	4.40	✓
To take a bath or shower by him/herself?		10	20	20	50	4.10	✓
To prepare food by him/herself?		40	40	20	0	2.80	×
To walk by him/herself?			10	50	40	4.30	✓
To keep his/her balance when bending?			33.3	22.2	44.4	4.07	✓
To climb stairs by him/herself?		22.2	44.4	11.1	22.2	3.30	✓
To write or type?		22.2	33.3	33.3	11.1	3.30	✓
To drive the car by himself?		55.6	44.4			2.44	×
To do buttons by him/herself?		22.2	44.4	22.2	11.1	3.19	✓
To open a jar or a can?	11.1	22.2	33.3	33.3		2.86	×
To express his/her opinion?				36.6	63.6	4.64	✓
Their family members understand them when they talk?				27.3	72.7	4.73	✓
Their friends understand them when they speak?				70	30	4.3	✓
To speak clearly in the phone?			50	30	20	3.7	✓
To join in conversation with other people?		27.3	18.2	36.4	18.2	3.42	✓
To speak to other people (strangers) in general?		9.1	54.5	27.3	9.1	3.33	✓
To find the word that they want to say straight away?				63.6	36.4	4.36	✓
To get other people understand them?			27.3	45.5	27.3	3.96	✓
To understand other's simple sentences?				45.5	54.5	4.50	✓
To tell their life stories?			63.6	27.3	9.1	3.45	✓
To follow news, sport on TV?		25	62.5	12.5		2.84	×
To do household activities (i.e. gardening, ironing)?	12.5		75.0	25		4.37	✓
To get out of the house and do things such as shopping and visiting others?			25	75		3.75	✓
To do some reading like Quran, newspapers and books?			25	62.5	12.5	3.83	✓
To participate in their community activities?	12.5	12.5	37.5	37.5		2.46	×
To go to Masjid to do the five prayers and attend the Friday prayer?			60	10	30	3.70	✓
To read the Holy Quran (Ayat) during the prayer?			40	40	20	3.80	✓
To do the prayers (that they missed at the Masjid), at home?			40	20	40	4.00	✓
To do the ablution (Wdoua) for the prayers?		10	10	50	30	4.00	✓
To read Quran by themselves out the prayer times?			50	40	10	3.60	✓
To memorize Quran and supplications during prayer?		10	20	60	10	3.70	✓
Their relationships with their partner (spouse)?				37.5	62.5	4.58	✓
Their relationships with their family members?				50	50	4.50	✓
Their relationship with their relatives?			12.5	75	12.5	3.96	✓
Their relationship with their boss at work?			87.5		12.5	3.21	✓
The relationship with their colleagues at work?			62.5	37.5		3.34	✓
Others' feeling sorry for and pitying them?		50	30	10	10	2.80	×
People accepting them?				10	90	4.90	✓
Their status at work?			40	30	30	3.90	✓
Their career path?		33.3	11.1	44.4	11.1	3.30	✓
Their family confidence on them?				20	80	4.80	✓
Their lives now after the incidence?			30	20	50	4.20	✓
× → less than average < 3 to be excluded***** ✓ → above average > 3 to be included							

## Appendix C: Documents of ethical considerations



مدينة سلطان بن عبد العزيز للخدمات الإنسانية  
SULTAN BIN ABDULAZIZ HUMANITARIAN CITY

To : Mr. Adel Fahad I. Jadaan  
PhD Student, Speech Sciences  
Institute of Neurosciences  
University of Newcastle upon Tyne

Date: 25<sup>th</sup> January 2011

Dear Mr. Jadaan:

Your Research Proposal on the Quality of Life Aphasic Stroke Patients was reviewed and approved by the Research & Ethics Committee during its meeting on 23<sup>rd</sup> January 2011 with minor corrections on the following items:

- 1) No signature on cover page from the Principal Investigator.
- 2) On Page 3, there was no information from the Official Authorization, no signature from your Head of Dept.

Please don't hesitate to contact Dr. Muwafak Al-Eithan, PhD, Chairman of the Research & Ethics Committee at Office Telephone No.: 00966-1-562-0000 Ext. 2868 email address: [maleithan@humanitariancity.org.sa](mailto:maleithan@humanitariancity.org.sa); for any assistance that can be of help upon resubmitting your research proposal.

This is for your kind information and guidance.

Thank you.

Sincerely yours,

Dr. Muwafak Al-Eithan, PhD.  
Chairman of Research & Ethics Committee/

Kingdom of Saudi Arabia  
Ministry of Health  
King Fahd Medical City



المملكة العربية السعودية  
وزارة الصحة  
مدينة الملك فهد الطبية

December 14<sup>th</sup> 2010  
ERRC Number: 10-023  
IRB Number: 10-114

Dear Mr. Adel Fahad Aljadaan,

It is my pleasure to inform you that the External Research Review Committee, a subcommittee of the Institutional Review Board, has approved your study titled: "Assessing the quality of life (QoL) for Saudi patients with aphasia after stroke."

Please be informed that in conducting this study, you as the Principal Investigator is required to abide by the rules and regulations of the Government of Saudi Arabia and KFMC/ERRC. The approval of this proposal will automatically be suspended on December 14<sup>th</sup> 2011 pending the reapplication to renew the approval. You also need to notify the ERRC as soon as possible in the case of:

1. Any amendments to the project;
2. Termination of the study.

Please observe the following:

1. Personal identifying data should only be collected when necessary for research;
2. The data collected should only be used for this proposal;
3. Data should be stored securely so that only a few authorized users are permitted access to the database;
4. Secondary disclosure of personal identifiable data is not allowed.

We wish you every success in your research endeavor.

If you have any further questions feel free to contact me.

Sincerely,

Mohamad Altannir, DMD, MPH  
Head of External Review Committee  
Institutional Review Board  
King Fahd Medical City, Riyadh, KSA  
Tel:9662889999 Ext.8391  
Email: maltannir@kfmc.med.sa

المرفقات

الرقم

التاريخ

INFORMED CONSENT

**INFORMED CONSENT (CLINICAL STUDY)**

<b>TITLE</b>	
Assessing the quality of life for Saudi patients with aphasia after stroke.	
<b>PRINCIPAL INVESTIGATOR</b>	
Adel Fahad Aljadaan	

Having discussed this research project with  
**Researcher.** Adel Fahad Aljadaan  
 and reviewed the OPEN LETTER, which is attached, I agree, voluntarily to the participation in this study:

<b>Patient's name</b>	
<b>Relationship</b>	

1. I understand that I will be participating in a study, which may, or may not benefit me directly, but will provide new knowledge, which could benefit other patients with similar conditions to mine in the future.
2. I also understand that I do have the right to withdraw from this study at any time, by telling my doctor/researcher. My decision to withdraw, or to decide not to participate, will in no way affect my ongoing treatment, to my relationship with my doctor.
3. I give permission for the doctor/researcher to read my medical records, and to publish or report the findings of this study at scientific meetings in the future, knowing that my identity will not be revealed. The doctor/researcher will explain the results of this study at the end.

<b>Signature</b>	
<b>Witness</b>	
<b>Investigator/Doctor</b>	

**موافقة خطية ( لدراسة إكلينيكية )**

<b>عنوان الدراسة</b>	
تقييم قيمة وجودة الحياة لدى مرضى العي من السعوديين وذلك نتيجة الإصابة بالجلطة الدماغية	
<b>الباحث الرئيسي</b>	
عادل بن فهد الجدعان	

بعد مناقشة بحث هذه الدراسة مع :  
**الباحث** عادل بن فهد الجدعان  
 ومراجعة المعلومات المنفصلة عن الدراسة المعرفة فلتني أوافق طوعاً على المشاركة في هذه الدراسة .

<b>اسم المريض</b>	
<b>العلاقة بالمريض</b>	

- 1- أنا أعلم بأنني سوف أشترك في هذه الدراسة ومن المحتمل أن تكون ذات فائدة بطريقة مباشرة أو غير مباشرة ولكنها سوف توفر معلومات يمكن أن تفيد مرضى آخرين يمثل حالتي في المستقبل.
- 2- بالإضافة إلى ذلك فإني أعلم بأنه لي الحق في الانسحاب في أي وقت من هذه الدراسة وذلك بإخطار طبيبي المعالج/الباحث بأنني قررت الانسحاب أو قررت عدم المشاركة ولن يؤثر ذلك على علاجي أو علاقتي بالطبيب المعالج
- 3- إنني قد فوضت الطبيب/الباحث بمراجعة ملفي الطبي ونشر أو تقديم نتائج الدراسة في المؤتمرات الطبية في المستقبل مع عدم ذكر اسمي. وفي نهاية الدراسة سيشرح لي الطبيب /الباحث نتائجها

<b>توقيع المريض</b>	
<b>شاهد</b>	
<b>الباحث /الطبيب</b>	

Appendix D: A sample interview from the semi-structured interview

KFMC
المستشفى:
المريض:

E
الجنس:
40 years - /
العمر:

S.S.I - M7
الرمز:
AJ
الأخصائي:

15.04.2011
15/4/2011
التاريخ:

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س1: ماهو الشيء/الاشياء التي تجعل حياتك جيدة الآن؟ هل هناك شيء آخر يجعلها كذلك؟

1. I am alive. thankful. بأنني أحيي. شاكراً. *بأنني أحيي*

2. to see my children around me. أن أرى أطفالي حولي *أن أرى أطفالي*

3. to have better children at home. أن يكون أطفالي أفضل *أن يكون أطفالي*

4. my husband's help and being patient with me. مساعدة زوجي في كل شيء *مساعدة زوجي*

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س2: ماهو الشيء/الاشياء التي تجعل حياتك سيئة الآن؟ هل هناك شيء آخر يجعلها كذلك؟

1. Not able to do things at home as before. غير قادر على فعل الأشياء المنزلية *غير قادر على فعل الأشياء*

2. I cannot help my children in schooling. لا أستطيع مساعدة أطفالي في المدرسة *لا أستطيع مساعدة أطفالي*

3. Not doing my duties for my husband. غير قادر على القيام بواجباتي لزوجي *غير قادر على القيام بواجباتي*

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س3: هل بإمكانك ذكر شيء أو أشياء قد يؤدي/تؤدي التي جعل حياتك أفضل مما هي عليه؟ هل هناك شيء آخر غير ذلك؟

1. I am happy. أنا سعيدة *أنا سعيدة*

2. take care of my children as before schooling. أخذ عني أطفالي *أخذ عني أطفالي*

3. to speak much better. أن أتكلم بشكل أفضل *أن أتكلم بشكل أفضل*

4. to do cooking and all my household work as before. أن أفعل الطبخ والعمل المنزلي *أن أفعل الطبخ والعمل المنزلي*

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س4: هل بإمكانك ذكر شيء أو أشياء قد يؤدي/تؤدي التي جعل حياتك أسوء مما هي عليه؟ هل هناك شيء آخر غير ذلك؟

1. My speech not improved. لست أرى تحسناً في كلامي *لست أرى تحسناً في كلامي*

2. Not able to move and walk better. غير قادر على التحرك والمشي *غير قادر على التحرك والمشي*

3. to have a stroke again. أن أصاب بجلطة دماغية أخرى *أن أصاب بجلطة دماغية أخرى*



## **Appendix E: Examples of patients' responses to the interview questions**

1- What makes your life good? Is there anything else that makes it good?

Thanks God for everything, everything in my life is good now.

To see my children around me, and play with them.

That I am alive not dead, I am much better than many others even younger, thanks God.

I am walking and not like others with the same problem.

My family (my wife and my sons and daughters) are taking care of me.

I can speak and communicate with others.

I can understand what is happening around me.

I can go outside by myself and participate with others.

When I see others who are worse than me and see myself I always thank God for this.

2- What makes your life bad? Is there anything else that makes it bad?

I cannot speak what is in my mind, I speak as drunk.

I cannot read or write, I cannot understand what I read, people laugh at my speech.

Still need somebody (my son or daughter) to be with me all the time to speak for me.

I cannot go to the bathroom by myself, still need help in cleaning due to weakness of my hand.

I cannot drive my car.

Just sitting at home, watching TV all day.

My relationship with most of the people that I know has changed, they do not contact me or ask any more.

When my son/daughter does not understand me, or just give me their back.

I cannot go to the Masjid or attend the Jumaah (Friday prayer) as before.

My relationship with my spouse (private life) not like before.

I cannot go out and do shopping by myself, I depend on my sister to do that for me, it is difficult to ask her to choose my private clothes (underwear). It is so embarrassing. It is so difficult.

I cannot do the homework with my children any more.

I cannot take care of my family as before.

I have been forced to retire early due to this problem. I cannot find a job.

I am staying at home all the time, I cannot go outside, I am tied to the house like a woman.

I cannot even write what I need; even if I know it, my handwriting is rubbish nobody understands what I want.

I forget many things and it takes me time to remember.

People think that I am drunk when they see my way of walking or my slow speech.

I am afraid to be alone, I am afraid that it will happen again (the stroke).

3- What things would make your life better? Would anything else make it better?

To speak or write what I want.

Other people understand what I am saying.

I can do things by myself. Go back to work and teach.

To have my wife who died two years ago. He cries; he missed her so much. Not like my children in spite of the fact they are doing their best to take care of him.

To walk again, without others' help.

To insure my children's future, so they do not need anybody's help.

To have a house for me and my family.

My children to have a good education, and good jobs.

4 -What things would make your life worse? Would anything else make it worse?

Whatever comes from God is accepted; even if it is worse I am satisfied.

If I would be paralysed and use a wheelchair for example (God forbid), thanks God.

If I would not be able to speak.

If would be bedridden like others.

If I would lose my mind and not understand or not know what is going on around me.

To have a stroke again.

5- Are there other things you would like to do but which are difficult for you? If yes, this question will be followed by: and what makes it difficult.

To clean myself in the bathroom because of the hand and leg weakness (hemi paralysis) that I have.

To speak easily with others, my tongue is heavy to move.

To drive the car, my hand weakness and my vision problem.

To walk and go outside whenever I want, using the wheelchair and not afraid of speaking with others by myself.

6- What are your wishes? To enjoy better QoL?

To be normal as before.

To speak easily with no difficulties.

Thanks God, I have everything that I want.

Not stay at home or find a job.

To work and not depend on the social welfare money or retirement pension salary.

To see my children (daughters and sons) married in my life.

7- Are you familiar with the term (quality of life)? If yes, what does it mean to you? How?

No I do not know what does it mean exactly but it may mean...

To be happy in your life

To be healthy and need nobody

To be self-sufficient in your all life

To have a good life (wife, house, job, car and good salary)

To be blessed by God and your parents

To have a little of everything

**Appendix F: Outcome of the interview findings with examples for the emerging themes & sub-themes**

Themes	An example of a sub-theme	Number of responses	An example
A-Physical difficulties	Dependency on others	8/11	PT1: I cannot dress myself; someone has to help me with that.
	Difficulty in Travelling	7/11	PT 7: I wish I could travel, so I can take the plane and go to Jordan to visit my son there (He had a son (autistic) who was treated at one of Jordan's rehabilitation centres).
B-Communication (speech and language):	Speaking to others	9/11	PT1: Speaking and talking is the biggest problem (he was pointing to his tongue).
	Memory problem	7/11	PT5: It takes me long time to say the word.
C-Interests and leisure	Outdoors activities	5/11	PT10: I wish I could go out for shopping as I used to do before with my sisters.
	Staying at home like a useless person	5/11	PT3: Just lying down tied to the house.
D-Religious duties	Reading and understanding of the Quran	8/11	PT5: I wish I could do the prayer as before because now I can't read the Quran in my prayer.
E-Social and family relationships	Continue their relationships with others as before	7/11	PT11: This accident showed me who my real friends are; I can call them brothers.
	Role in the family	6/11	PT4: The do not obey me as before.
F-Feelings and emotions	Loss of respect and importance in the society	9/11	PT5: I do not like to go to parties because most people there treat me like a patient.
	Nature of private life with the spouse	6/11	PT 6: My relationship with my husband is not as before (because of her problem now, they have different rooms).
	Feeling lucky they are alive	5/11	PT2: Thanks God that I am alive and not dead.

**Appendix G: Modified VR2 of the questionnaire**

ITEM CODE	QUESTIONS : In the last two weeks How easy was it for you ...(before the targeted item)	COULD NOT AT ALL	A LOT OF DIFFICULTY	SOME DIFFICULTY	QUITE EASY	VERY EASY	N /A
A-PHYSICAL &DAILY LIFE ACTIVITIES		1	2	3	4	5	
1 A	To get dressed by yourself	1	2	3	4	5	
2 A	To take a bath or shower by yourself	1	2	3	4	5	
3 A	To help yourself with cleaning at the toilet and cover yourself	1	2	3	4	5	
4 A	To walk by yourself	1	2	3	4	5	
5 A	To keep your balance when bending over or reaching	1	2	3	4	5	
6 A	To climb the stairs by yourself	1	2	3	4	5	
7 A	To stand to get out of the chair	1	2	3	4	5	
8 A	To write or type	1	2	3	4	5	
9 A	To do a zip by yourself	1	2	3	4	5	
10 A	To walk for a while on a daily basis	1	2	3	4	5	
11 A	To be dependent on yourself not on others in your daily life activities	1	2	3	4	5	
Sub-total Score							

ITEM CODE	QUESTIONS : How important is it to you that ...(before the targeted item)	NOT IMPORTANT AT ALL	NOT IMPORTANT	NEUTRAL	IMPORTANT	VERY IMPORTANT	N/A
B –Communication		1	2	3	4	5	
1 B	you can express your opinion?	1	2	3	4	5	
2 B	your family members understand you when you talk?	1	2	3	4	5	
3 B	your friends understand you when you talk?	1	2	3	4	5	
4 B	you speak clearly on the phone?	1	2	3	4	5	
5 B	you speak to other people (strangers ) in general?	1	2	3	4	5	
6 B	you join in a conversation with a group of people?	1	2	3	4	5	
7 B	you find the words you want to say directly?	1	2	3	4	5	
8 B	you can tell your life stories?	1	2	3	4	5	
9 B	you get other people to understand you?	1	2	3	4	5	
10 B	you understand others' simple /short spoken information/sentence?	1	2	3	4	5	
11 B	you show that you do not understand something?	1	2	3	4	5	
Sub-total Score							

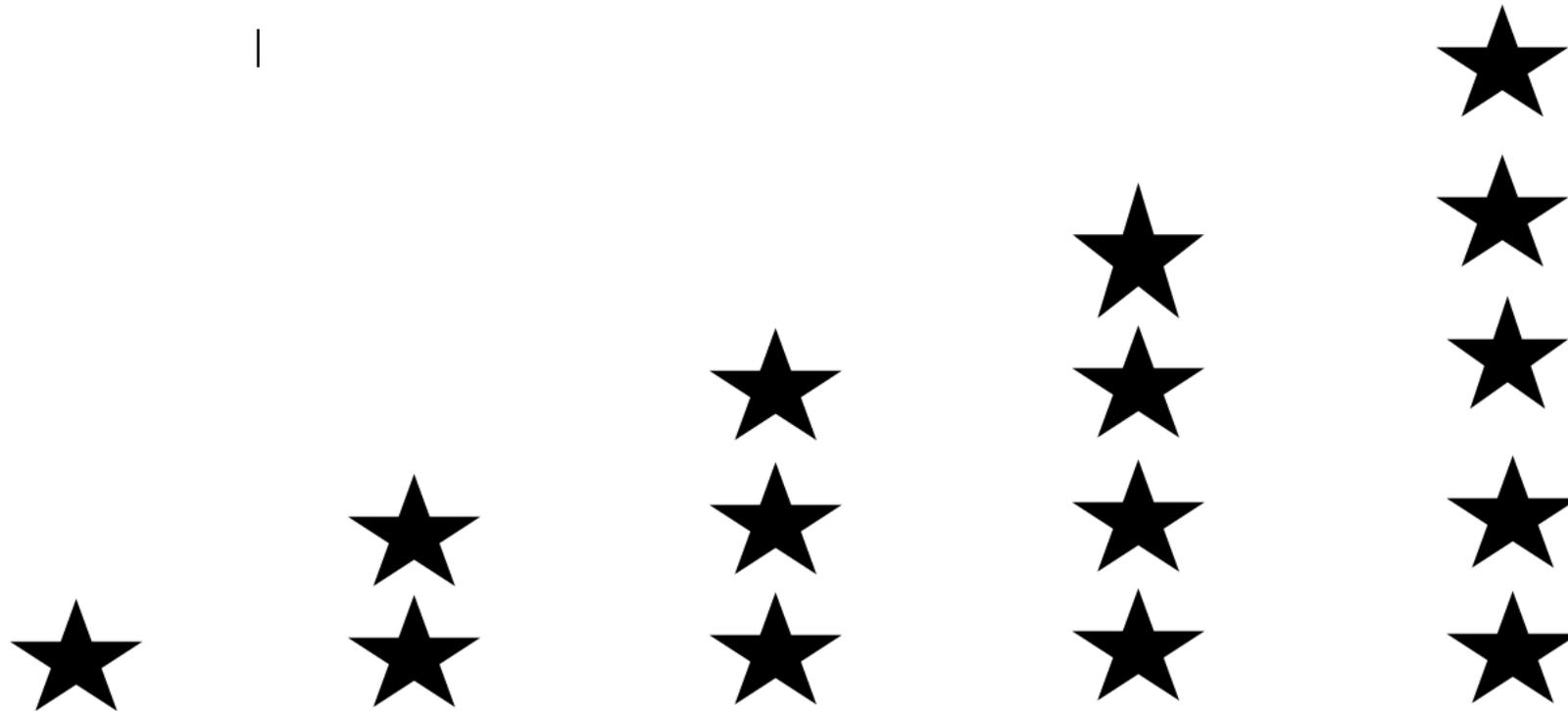
ITEM CODE	QUESTIONS: In the last two weeks, how easy was it for you ... (before the targeted item)	COULD NOT AT ALL	A LOT OF DIFFICULTY	SOME DIFFICULTY	QUITE EASY	VERY EASY	N/A
C – Interests and leisure		1	2	3	4	5	
1 C	To follow the news, sports on TV?	1	2	3	4	5	
2 C	To do household activities (i.e. gardening, ironing)?	1	2	3	4	5	
3 C	To get out of the house and do things such as shopping, sports, social gathering, visiting family members/ friends or going out to the desert?	1	2	3	4	5	
4 C	To do some reading like the Quran, newspapers, magazines, books, as you used to do before?	1	2	3	4	5	
5 C	To share/participate in your community activities (marriage occasions, social clubs, voluntary jobs ...)?	1	2	3	4	5	
Sub-total Score							

ITEM CODE	QUESTIONS: In the last two weeks, how easy was it for you ... (before the targeted item)	COULD NOT AT ALL	A LOT OF DIFFICULTY	SOME DIFFICULTY	QUITE EASY	VERY EASY	N/A
D- Religious activities		1	2	3	4	5	
1 D	To go to the Mosque (Masjed) for five prayers to attend the (ja-ma-ah) group prayer? *(M)	1	2	3	4	5	
2 D	To do the prayers that you cannot do at the Mosque (Masjed) individually?	1	2	3	4	5	
3 D	To read the Holy Quran (Aayat) during the prayers?	1	2	3	4	5	
4 D	To read the Holy Quran individually (not in the Prayer times)?	1	2	3	4	5	
5 D	To do <u>ablution</u> (wdou-a) for the religious duties?	1	2	3	4	5	
6 D	To do the voluntary prayers (sun-ah )	1	2	3	4	5	
7 D	To memorize (Aayat)and (Du-aa) during the prayers?	1	2	3	4	5	
Sub-total Score							

ITEM CODE	QUESTIONS: How do you see your relationship with... (before the targeted item)	NOT GOOD AT ALL	NOT GOOD	NEUTRAL	GOOD	VERY GOOD	N/A
E - Social relationships		1	2	3	4	5	
1 E	Your partner (spouse)?	1	2	3	4	5	
2 E	Your family members?	1	2	3	4	5	
3 E	Your relatives?	1	2	3	4	5	
4 E	Your boss at work?	1	2	3	4	5	
5 E	Your colleagues at work?	1	2	3	4	5	
Sub-total Score							

ITEM CODE	QUESTIONS: Now, how do you feel about ...(before the targeted item)	NOT GOOD AT ALL	NOT GOOD	NEUTRAL	GOOD	VERY GOOD	N/A
F-Feelings and emotions		1	2	3	4	5	
1 F	Accepting people to you?	1	2	3	4	5	
2F	Your status at work?	1	2	3	4	5	
3F	Your career path?	1	2	3	4	5	
4 F	Keeping in touch with your colleagues and friends as they were before the problem?	1	2	3	4	5	
5 F	Being treated like a normal person not like a patient?	1	2	3	4	5	
6 F	To feel that your value among your people has not been changed due to this problem?	1	2	3	4	5	
7 F	You are supported by the people around you?	1	2	3	4	5	
8 F	Your family's confidence in you?	1	2	3	4	5	
9 F	Your life now?	1	2	3	4	5	
Sub-total Score							

**Appendix H: Visual analogue scale**



Could not do it at all	A lot of difficulty	Some difficulty	Quite easy	Very easy
1	2	3	4	5



Not good at all	Not good	Neutral	Good	Very good
1	2	3	4	5

## **Appendix I: Findings of the questionnaire**

A-Physical and daily life activities domain:

1A-To get dressed by yourself → To get dressed by yourself (in general). Seven out of 11 participants asked about the type of clothes the question referred to, e.g. sports or casual clothes, traditional wear or western, or easy to wear a dress by the female participants because the degree of difficulty depends on the type of clothes. Most of the patients adapted to this problem by choosing what was easier and convenient for them.

4A-To walk by yourself → To walk by yourself? (Even with a stick or walker). Five out of 11 patients asked if the question meant walking with or without support, such as a stick or walker. The distance also made a difference for the patient.

8A-To write or type → To write or type (with the hand that you used before)? Five out of 11 patients asked about the hand to which the question referred. Their answers depended on which hand they were currently using, and which they were using before, for a particular purpose or as a means of communication. They had started to train the other hand to cope in this matter.

9A-To do a zip by yourself → To do a zip (for females, as it is more common) and to do a button (for males, when dressing the traditional dress). It depended on the type of clothing used and to be specific.

10A-To walk for a while on a daily basis. → 11A- To walk for a while for (5-10 min.) on a daily basis. Eight out of 11 patients stated that it depended on how long the question intended.

12A-To drive the car by yourself → To drive the car by yourself as before\* (males) was added, because women do not drive cars in Saudi Arabia.

11A-To be dependent on yourself and not on others in your daily life activities. → 13A-To be independent from others in your daily life activities. This question was rephrased to make it easier and clearer for the patient to understand and for the researcher to ask.

B-For the communication domain:

1B-To express your opinion → To express your opinion, by all means. Six out of 11 patients said they could express their opinion verbally, while others used non-verbal communication, depending on the severity of their speech difficulty.

6B-To join in conversation with a group of people → To join in conversation with a group of people? (In general, friends, relatives, and strangers). Seven out of 11 said it depended on whether the people in the group were known to them and to what extent.

C-For Interests and leisure domain:

1C-To follow the news, sports on TV → To follow the news, sports on TV as you used to before. Seven patients said they followed them but not like before, or said that their watching habits had changed overtime.

2C-To do household activities (i.e. gardening, ironing) → To do household activities (i.e. gardening, house cleaning, cooking, ironing) as you used before. The female patients, described house cleaning and cooking as a hobby they used to do but said that the way they practised it had changed after the accident.

No changes happened to the three questions which were added to the questionnaire from the interviews earlier for this section:

6C-To play with your children as before

7C -To travel to other places as before

8C- To do some sports or hobbies as before

D-For the religious activities domain:

2D- To do (perform) prayers at home? **\*\*For females**, who perform prayers at home, this question had to be added.

5D- To do ablution (wdou-a) for the religious duties → 6D- To do ablution (wdou-a) with water for the religious duties. The word water was mentioned here because there is an

alternative form of ablution without using water, and that was questioned by some patients.

E-For the social relationships domain:

4E- Your boss at work →5E- Your boss at work? (Teachers, lecturers...). Some of the patients were students and not working so, lecturers and teachers were considered to be their boss.

5E- Colleagues at work →6E- Colleagues at work? (University, institute...). Some patients were students and not working as mentioned before.

4E- Your neighbours/ friends. These had to be added because, according to eight patients, neighbours/ friends are different from relatives yet still within the range of people with whom they come into contact.

F-For the feelings and emotions domain:

4F- You are keeping in touch with your colleagues and friends as they were before the problem. It was divided into two questions →4F- You are keeping in touch with your colleagues as they were before the problem.

And →5F - You are keeping in touch with your friends as they were before the problem.

Six patients asked if the question meant friends or colleagues because they are different.

No change to the question which was added from the interviews, which is 8F-Your private life with your partner. As indicated, six out of the eleven patients' private lives had been affected by this problem.

**Appendix J: The final version of the questionnaire (VR3)**

ITEM CODE	QUESTIONS : In the last two weeks, how easy was it for you ...(before the targeted item)	COULD NOT DO IT AT ALL	A LOT OF DIFFICULTY	SOME DIFFICULTY	QUITE EASY	VERY EASY	N /A
A-PHYSICAL & DAILY LIFE ACTIVITIES		1	2	3	4	5	0
1 A	To get dressed by yourself? (in general)	1	2	3	4	5	0
2 A	To take a bath or shower by yourself?	1	2	3	4	5	0
3 A	To help yourself with cleaning at the toilet and cover yourself?	1	2	3	4	5	0
4 A	To walk by yourself? (even with stick or walker)	1	2	3	4	5	0
5 A	To keep your balance when bending over or reaching	1	2	3	4	5	0
6 A	To climb the stairs by yourself?	1	2	3	4	5	0
7 A	To stand to get out of the chair?	1	2	3	4	5	0
8 A	To write or type (with the hand that you used before)?	1	2	3	4	5	0
9 A	To do a zip (F)/ a button by yourself (M)?	1	2	3	4	5	0
10 A	To style your hair (F) /your Ghutrah (m)	1	2	3	4	5	0
11 A	To walk for a while (5-10 min) on a daily basis?	1	2	3	4	5	0
12 A	To drive the car by yourself as before? **(Males)	1	2	3	4	5	0
13 A	To be independent from the others in your daily life activities	1	2	3	4	5	0
Sub-total Score							

Appendices

ITEM CODE	QUESTIONS : In the last two weeks, how easy was it for you ... (before the targeted item)	COULD NOT DO IT AT ALL	A LOT OF DIFFICULTY	SOME DIFFICULTY	QUITE EASY	VERY EASY	N /A
B –Communication		1	2	3	4	5	0
1 B	To express your opinion? By all means	1	2	3	4	5	0
2 B	To make your family members understand you when you talk?	1	2	3	4	5	0
3 B	To make your friends understand you when you talk?	1	2	3	4	5	0
4 B	To speak clearly on the phone?	1	2	3	4	5	0
5 B	To speak to other people (strangers) (in general)?	1	2	3	4	5	0
6 B	To join in conversation with a group of people?(in general, friends relatives strangers)	1	2	3	4	5	0
7 B	To find the word you want to say directly?	1	2	3	4	5	0
8 B	To tell your life stories?	1	2	3	4	5	0
9 B	To get other people to understand you?	1	2	3	4	5	0
10 B	That you understand others' simple commands /short spoken information /sentence?	1	2	3	4	5	0
11 B	To show that you do not understand something?	1	2	3	4	5	0
Sub-total Score							

Appendices

ITEM CODE	QUESTIONS : In the last two weeks, how easy was it for you that ...(before the targeted item)	COULD NOT DO IT AT ALL	A LOT OF DIFFICULTY	SOME DIFFICULTY	QUITE EASY	VERY EASY	N/A
C – Interests and leisure		1	2	3	4	5	0
1 C	To follow the news ,sports on T.V as you used to before	1	2	3	4	5	0
2 C	To do house hold activities (i.e. gardening, house cleaning, cooking ironing) as you used to before?	1	2	3	4	5	0
3 C	To get out of the house and do things such as (shopping, sports, social gathering, visiting family members/friends or going out to the desert)?	1	2	3	4	5	0
4 C	To do some reading like the Quran, newspapers, magazines, books, as you used to do before?	1	2	3	4	5	0
5 C	To share/participate in your community activities (marriage occasions, social clubs, voluntary jobs	1	2	3	4	5	0
6 C	To play with your children as before?	1	2	3	4	5	0
7 C	To travel to other places as before?	1	2	3	4	5	0
8 C	To do some sports or hobbies as before?	1	2	3	4	5	0

Appendices

ITEM CODE	QUESTIONS : In the last two weeks, how easy was it for you ...(before the targeted item)	COULD NOT DO IT AT ALL	A LOT OF DIFFICULTY	SOME DIFFICULTY	QUITE EASY	VERY EASY	N/A
D- Religious activities		1	2	3	4	5	0
1 D	To go to Mosque (Masjid) for five prayers to attend the (ja-ma-ah) group prayer? ** <i>(M)</i>	1	2	3	4	5	0
2D	To do (perform) the prayer at home? ** <i>(Females)</i>	1	2	3	4	5	0
3 D	To do the prayers that you cannot do at the Mosque (Masjid) individually?	1	2	3	4	5	0
4 D	To read the Holy Quran (Aayat) during the prayers?	1	2	3	4	5	0
5D	To read the Holy Quran individually (not in the Prayer times) (voluntary reading)	1	2	3	4	5	0
6D	To do ablution (Wadou-a) with water for the religious duties?	1	2	3	4	5	0
7D	To memorize (Aayat) and (Du-aa) during the prayers?	1	2	3	4	5	0
8 D	To eat with the right hand?	1	2	3	4	5	0
9 D	To shake hands with the right hand?	1	2	3	4	5	0
Sub-total Score							

Appendices

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\*\*\*Change the scoring sheet

ITEM CODE	QUESTIONS : How do you see, your relationship with ...(before the targeted item)	NOT GOOD AT ALL	NOT GOOD	NEUTRAL	GOOD	VERY GOOD	N/A
E - Social relationships		1	2	3	4	5	0
1 E	Your partner (spouse)? In general	1	2	3	4	5	0
2 E	Your family members?	1	2	3	4	5	0
3 E	Your relatives?	1	2	3	4	5	0
4 E	Your neighbours/ friends?	1	2	3	4	5	0
5E	Your boss at work? (teachers, lecturers...)	1	2	3	4	5	0
6E	Colleagues at work? (university, institute...)	1	2	3	4	5	0
Sub-total Score							

Appendices

ITEM CODE	QUESTIONS : Now, how do you feel about ...(before the targeted item)	NOT GOOD AT ALL	NOT GOOD	NEUTRAL	GOOD	VERY GOOD	N/A
F-Feelings and emotions		1	2	3	4	5	0
1 F	Accepting people to you?	1	2	3	4	5	0
2F	Your status at work? Or Occupation?	1	2	3	4	5	0
3F	Your career path/ study?	1	2	3	4	5	0
4 F	Keeping in touch with your <u>colleagues</u> as they were before the problem?	1	2	3	4	5	0
5 F	Keeping in touch with your <u>friends</u> as they were before the problem	1	2	3	4	5	0
6F	Being treated like a normal person not like a patient?	1	2	3	4	5	0
7 F	Feeling that your value among your people not been change due to this problem?	1	2	3	4	5	0
8 F	Your private life with your partner?	1	2	3	4	5	0
9F	Being supported by the people around you?	1	2	3	4	5	0
10 F	Your family's confidence in you?	1	2	3	4	5	0
11F	Your life now?	1	2	3	4	5	0
Sub-total Score							

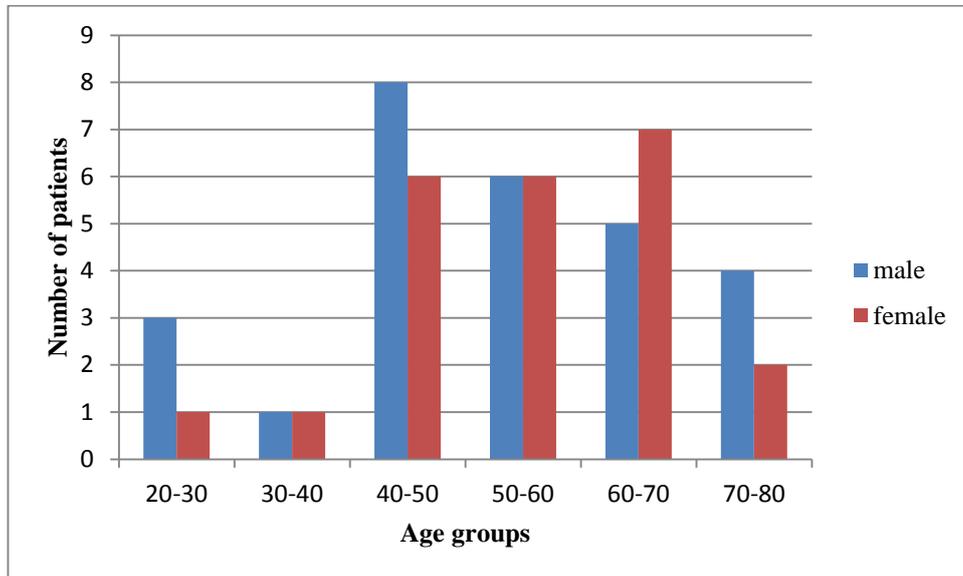
**Appendix K: Characteristics of the four missing subjects**

Characteristics	N=4	Per cent
Age		
Average	67 years	
Range	63-70 years	
Gender		
Male	3	75
Female	1	25
Severity		
Moderate	1	25
Severe	3	75
Stroke type		
Ischemic	3	75
Haemorrhage	1	25
Marital status		
Married	2	50
Widow	2	50
Post-time of onset		
Average	64 month	
Education level		
Illiterate	3	75
Able to read and write	1	25
Employment status		
Unemployed	3	75
Retired	1	25
Socio-economic status		
Average	3	75
High	1	25
Companion attendance		
With a companion	2	50
Without a companion	2	50

**Appendix L: Number of patients and possible reasons for each of the 18 missed items**

S.No	Item No.	Item/ question	No. Pt.	Possible reasons to be missed
1	7A	Stand to get out of the chair	2	-The patient can walk without assistance -The patient has no physical difficulties such hemi-paresis or hemi-paralysis
2	8A	Write or type	18	-13patients of the sample were illiterate -Other five patients have hemi-paresis/paralysis on the hand they use for writing/typing
3	12A	Drive the car (M)	24	-23 patients of the sample were females who do not drive cars, while 27 patients were males -The patient has a driver instead
4	2C	Do household activities	19	-23 patients are females who used to do the household activities as housewives. So 15/23 patients do not do these activities any more due to their physical difficulties -Four out of 27 male patients who used to do some gardening do not do it anymore after the incident due to physical difficulties involved
5	4C	Do some reading like the Quran	19	-13 patients were illiterate -Four patients feel that they do not understand what they read -Two patients have reading difficulties
6	6C	Play with children	7	-Four patients have no children -Three patients are single
7	8C	Do some sport	18	-13 patients are females who did not use do any sport before or after the incidence -Five patients are over 70 years old
8	1D	To go to Mosque (Masjid) for five prayers (M)	23	-23 patients are females which is not apply to them to the prayer at the Masjid
9	2D	To do the prayers at home (F)	30	-It is not applicable for male patients. 27 patients are males -Three females patients cannot do it at home because they believe that they will not do it properly because they do not know what to say in it
10	3D	Do prayers you cannot do at Masjid (M)	23	It is not applicable for females. There are 23 females in total
11	5D	Read the Quran as a voluntary reading	19	-13 patients who are illiterate - Six patients have a sight problem
12	1E	Relationship with your partner (spouse)	14	Ten patients are widows Three patients are single One patient is divorced
13	5E	Relationship with your boss at work	42	22 patients are unemployed 17 patients are retired Two patients are students One self employed
14	6E	Relationship with your colleagues at work	42	22 patients are unemployed 17 patients are retired Two students One self employed
15	2F	Your status at work	42	22 patients are unemployed 17 patients are retired 3 patients are students
16	3F	Your career path	42	22 patients are unemployed 17 patients are retired Two are students One is self employed
17	4F	Keeping in touch with your colleagues	23	22 patients are unemployed One patient is self-employed
18	8F	Your private life with your partner	14	Ten patients are widow Three patients are single One patient is divorced

### Appendix M: Number of participants by age group and gender



**Appendix N: The 21-item version of the questionnaire**

S. No	Factor	Item	Statement of the item/question
1	1	Q4A	Walking by yourself
2		Q5A	Balancing when bending over or reaching
3		Q6A	Climbing the stairs
4		Q13A	Being independent
5		Q2A	Taking a bath or shower
6		Q1A	Getting dressed
7		Q7C	Travelling to other places
8	2	Q3B	Having your friends understand you when you talk
9		Q8B	Telling stories about your life
10		Q11B	Showing others that you do not understand
11		Q6B	Joining others in a conversation
12		Q4B	Speaking clearly on the phone
13		Q1B	Expressing your opinion
14		Q7B	Finding the words that you want to say
15	3	Q3E	Your relationship with your relatives
16		Q2E	Your relationship with your family members
17		Q10F	Your family's confidence in you
18		Q9F	Being supported by the people around you
19		Q5F	Keeping in touch with your friends
20		Q6F	Being treated like a normal person
21		Q11F	Your life now



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