Exploring goal-setting in aphasia rehabilitation within the cultural context of experiencing stroke and aphasia from the viewpoints of people with aphasia, their family members, and speech and language therapists in Saudi Arabia: Advocating a context-sensitive approach to goal-setting

Hanadi Ali Albatati

A thesis submitted in partial fulfilment of the requirements for the
degree of
Doctor of Philosophy

The University of Sheffield
Faculty of Medicine, Dentistry and Health
Health Sciences School
Division of Human Communication Sciences

July 2020

Acknowledgements

This thesis was finalised during the most challenging time, the COVID-19 quarantine. At this time, I was working on my thesis between the UK and Saudi Arabia and I experienced drastic changes where the world was fighting the pandemic; cities were locked down, curfews were imposed and social distancing was a necessary requirement. I experienced not only the pressure of finalising a PhD thesis, but also the pressure of trying to manage this process considering what the whole world was going through. Thanks to God for giving me the strength and capacity. I consider myself strong, resilient, and lucky to be able to finish at these times.

Many people have supported me during my PhD years and while writing my thesis during this difficult time. My deep gratitude goes first to my first supervisor, Dr Ruth Herbert, who supported me endlessly during my PhD years. Her expertise, guidance, patience, and belief in me motivated me to give my best. Her support was provided to me at the academic level and at a personal level during the pandemic. Thank you, Dr Herbert, for all your support and for your precious time spent reading my thesis and providing comments on my writings. I consider myself very fortunate because I had the opportunity to work with a knowledgeable, committed, considerate supervisor like you.

I would like also to thank and express my sincere gratitude to Dr Catherine Tattersall, my second supervisor. Thank you, Dr Tattersall, for all your support during these long years. Thank you for your encouragement and valuable feedback on the project.

I would also like to say thanks to my family; words fail to express my appreciation to them. Thank you, my parents, Ali and Zenah, without you I would not have had the courage to go through this journey. Thank you for believing in me and in my abilities. Thank you for always being there for me if I asked or even if I did not. Thank you for always supporting me, loving

me unconditionally, and making me feel safe and secure. Thanks to my siblings, Hebah, Faisal, Hadeel, and Hanouf, for also being there and supporting me though my PhD journey. Thank you for filling my life with joy, fun and support.

I would also like to thank my friends who were part of my PhD journey. Thank you, Haya; you were super supportive, understanding and caring. Thanks for the fun we had and for all the philosophical talks. Thank you, my friend Indri, who also was always supportive and always there when I needed. Thank you, Indri, for your constant encouragement, understanding, and the fun trips we had. Thanks to all my friends and colleagues who supported me during my PhD journey.

Abstract

Background

Research into the experience of stroke and aphasia has highlighted the physical, emotional and social burdens on people with aphasia (PWA) and their family members, with research mainly conducted in Europe, the USA and Australia. Revealing the experience of PWA can inform research and clinical practice. In clinical practice, goals are fundamental aspects to the provision of aphasia therapy. The existing literature in the area of therapeutic goals has revealed the views of PWA, their family members and speech and language therapists (SLTs) on goals and goal-setting in the same geographical regions. However, there is no evidence in the literature of studies that have investigated the experience of stroke and goal-setting in aphasia therapy in Saudi Arabia.

Aim

This study aims to explore therapeutic goal-setting in aphasia rehabilitation within the cultural context of experiencing stroke and aphasia in Saudi Arabia.

Methods

In-depth, semi-structured, individual interviews were conducted with 29 participants who constitute 11 triads. Each triad involved a person with aphasia, a family member and the SLT in charge of the case. Data from PWA’s case records were also collected. Thematic analysis and grounded theory techniques were used to analyse the data.

Results

From the data six major themes emerged which are related to the experience of stroke and aphasia, and goal-setting in aphasia rehabilitation in Saudi Arabia. The major themes are as follows: Stroke occurrence and the social context, The impact of stroke and aphasia, Identifying therapeutic goals, Participation in goal-setting, Expectations in aphasia therapy, and The nature of goals in aphasia therapy. Based on the findings of themes, a conceptualisation of goal-setting in Saudi aphasia rehabilitation is presented.

Conclusion

Exploring the cultural context of the experience of stroke and aphasia provided a new perspective into goal-setting in aphasia rehabilitation that was not reported previously in the literature. The findings suggest that goal-setting in Saudi aphasia rehabilitation is highly context-based, and that the cultural aspect contributes to the dynamics of that process (Islamic faith and collectivism). The findings also suggest that goal-setting in Saudi aphasia rehabilitation is informal and the complexity of it directs the process to be therapist-led. The findings emphasise the role of SLTs in empowering and supporting PWA and their family members in aphasia rehabilitation in a context-sensitive way. It is suggested that supporting the effective involvement of PWA and their family members in the process of goal-setting facilitates reaching matched expectations; thus, increasing motivation, cooperation, and commitment to aphasia therapy.

The current study advocates contextual transparency in research and a context-sensitive approach to goal-setting in aphasia rehabilitation.

Table of content

List of tables

List of figures

Chapter 1 Literature Review

1.1 Background

People with aphasia (PWA), accompanied by their family members, attend aphasia therapy sessions which are conducted against the background of the context of their own experience of undergoing stroke and living with aphasia. Research on the experience of stroke and aphasia has highlighted the physical, emotional and social burdens on stroke survivors/PWA and their family members, with research having mainly been conducted in Europe, the USA, and Australia (e.g. Greenwood & Mackenzie, 2010; Hesamzadeh, Dalvandi, Bagher Maddah, Fallahi Khoshknab, & Ahmadi, 2015; Luker et al., 2017; Nasr et al., 2016; Simeone et al., 2015). Armstrong, Hersh, Hayward, Fraser, and Brown, (2012) suggested that revealing the experience of PWA is critical in understanding the culture of PWA and then being able to provide relevant and sensitive services. For example, exploring the experience of Indigenous Australian people living with aphasia whom views are not reported widely in the literature can inform research and clinical practice for PWA from this specific culture and other similar cultures (Armstrong, Hersh, Hayward, Fraser, and Brown, 2012). Such research revealed that Indigenous Australian PWA live in a more collectivist culture where community decision making can be strongly present in comparison to individual autonomy, and where more value is placed on social participation in comparison to traditional speech and language therapy (Armstrong, Hersh, Hayward, Fraser, and Brown, 2012). Hence, more understanding to other's cultures can be achieved and more sensitive services can be provided.

Therapeutic goals in clinical practice is an aspect that is fundamental to the provision of aphasia therapy. It has been suggested in the literature that clinical and aphasia therapeutic goals are context-based (Bradley, Bogardus, Tinetti, & Inouye, 1999; Hersh et al., 2012a). Moreover, it has been suggested that clinical goal-setting is a complex process (Bradley, Bogardus, Tinetti, & Inouye, 1999), and that the involvement of individuals receiving clinical services in clinical decision-making is context-based (Thompson, 2007). The existing literature on therapeutic goals and the process of goal-setting in stroke and aphasia rehabilitation has revealed the views of stroke survivors/PWA, their family members, and health care providers/SLTs in the same limited number of geographical regions including the UK, Norway, and Australia (e,g, Berg et al., 2017; Brown et al., 2014; Hersh et al., 2012a; Howe et al., 2012; Levack et al., 2009; Levack, Dean, Siegert, & Mcpherson, 2011; Parsons, Plant, Slark, & Tyson, 2016; Rohde, Townley-O'Neill, Trendall, Worrall, & Cornwell, 2012b; Rosewilliam, Sintler, Pandyan, Skelton, & Roskell, 2016; S Sherratt et al., 2011; Worrall et al., 2011).

Stroke rehabilitation guidelines published in Canada, New Zealand, Australia, and the UK have placed emphasis on providing services, including goal-setting, that are sensitive to the culture of stroke survivors (Hebert et al., 2016; Stroke Foundation, 2010, 2017), and that are sensitive to stroke survivors' and family members' desires (Rudd, Bowen, Young, & James, 2017). However, there is a lack of research that explores therapeutic goal-setting in countries other than English-speaking or Western countries, and from a wider perspective including taking into account the cultural context of people's experience in the research. Such research is needed in order to understand complex phenomena, build contextually transparent literature concerning aphasia rehabilitation, and to provide context-sensitive clinical services to PWA, who derive from different backgrounds to each other and often to that of the SLT.

Given the assumption that knowledge of the experience of stroke and aphasia across different cultures is valuable information which can inform clinical practice, that therapeutic goal-setting is complex and context-based, and that the Saudi cultural context differs from those investigated to date in the literature, this study aims to explore therapeutic goal-setting in aphasia rehabilitation within the context of the experience of stroke and aphasia in Saudi Arabia. The study investigates these phenomena within the triad of people typically involved in the rehabilitation process – the person with aphasia, their family member, and their speech and language therapist (SLT).

1.2 Introduction

In this chapter, an exploration of the literature related to the research context is presented. An overview of aphasia types and the relationship between stroke and aphasia are provided. Then, an overview of aphasia and stroke in Saudi Arabia is presented and aphasia is discussed in relation to research methodologies. This will be followed by information detailing background of qualitative research, and the application of this research methodology in aphasia research. Then, the experience of stroke and aphasia from the perspectives of stroke survivors and families are presented, and goal-setting in medical rehabilitation is discussed with an overview of studies found in the literature related to neurological/stroke and aphasia rehabilitation. This chapter concludes by stating the aims of the current research project.

1.3 Aphasia: Definition and types

Aphasia is an acquired neurogenic language disorder that occurs as a result of a brain lesion and affects the comprehension and formulation of language components (phonology, morphology, syntax, semantics and pragmatics) across all modalities including speaking, reading, writing and signing (Papathanasiou, 2017; Sarno, 1998). As a consequence of aphasia, expressive and receptive language deficits arise in people with this disorder. These deficits are exhibited in the form of specific signs that are reported in the literature. These signs include disturbances in naming, fluency, repetition, auditory comprehension, grammatical processing, reading, and writing (Sarno, 1998).

In aphasiology, the Boston classification is widely used because it describes the most frequent aphasia profiles encountered in clinical practice (Sarno, 1998). The Boston classification system is based on describing variation in verbal modality and comprehension severity (Davis, 1993). The major aphasia types include Broca's, Wernicke's, conduction, transcortical motor and sensory, anomic, and global aphasia (Sarno, 1998). With advanced medical imaging technology, these patterns of aphasia profiles have been linked to specific discrete brain lesion sites. Broca's, transcortical motor, and global aphasia were categorised under non-fluent aphasia, while Wernicke's, transcortical sensory, anomic, and conduction aphasia were grouped under fluent aphasia (Sarno, 1998).

With regard to non-fluent aphasia, Broca's, transcortical motor, and global aphasia are characterised by effortful, non-fluent speech with naming difficulties. Global aphasia includes severe difficulty in all language functions including comprehension and repetition. Meanwhile, in Broca's and transcortical motor aphasia, comprehension is relatively preserved, whereas repetition is impaired in Broca's aphasia, albeit preserved in transcortical motor aphasia (Papathanasiou, 2017).

In fluent aphasia, both conduction and anomic aphasia are characterised by preserved comprehension and by naming difficulties. Repetition deficits and paraphasias (unintended syllables, words or phrases) are present in conduction aphasia, whereas frequent pauses and circumlocution are present in anomic aphasia. With regard to both Wernicke's and transcortical sensory aphasia, comprehension is compromised and speech is characterised by the presence of paraphasia. Repetition is preserved in transcortical sensory aphasia, whereas it is mostly impaired in Wernicke’s aphasia (Papathanasiou, 2017).

1.4 Aphasia as a result of stroke

Aphasia is most commonly caused by stroke (Brady, Kelly, Godwin, Enderby, & Campbell, 2016; “RCSLT Resource Manual for Commissioning and Planning Services for SLCN,” 2014). In the developed world it has been suggested that the prevalence of aphasia is increasing due to the increase in stroke survival rate (Code & Petheram, 2011). The incidence of aphasia in the developed world is estimated to range between 0.02% and 0.06%, while the prevalence thereof is estimated to range between 0.1% and 0.4% (Code & Petheram, 2011). In the UK, more than 100,000 stroke cases occur annually, and the number of stroke survivors is reported to be nearly 1.2 million; approximately one third of individuals who survive stroke suffer from aphasia (Stroke Association, 2018). Prevalence and incidence will differ across different countries however, determined by factors including diet and lifestyle. The following section presents the current state of stroke and aphasia in Saudi Arabia, as evidenced in the literature, which is central to this study.

1.5 Stroke and aphasia in Saudi Arabia

In the following two sub-sections, information about stroke and aphasia epidemiology and rehabilitation services in Saudi Arabia are presented to provide an overview of the current state.

1.5.1 Epidemiology

The Kingdom of Saudi Arabia (KSA) occupies a large area of the Arabian Peninsula, covering a land area of around 2,000,000 square kilometres (General Authority for Statistics, 2018). The estimated population, including Saudis and non-Saudis, was reported to be approximately 34,218,169 in the middle of 2019 (Saudi General Authority for Statistics, 2019).

Stroke in Saudi Arabia is a health issue that is increasing rapidly in terms of incidence, as well as being a main factor affecting the health and life of individuals who survive stroke (Al-Jadid & Robert, 2010). It has been reported in the literature that hypertension, diabetes mellitus, and cardiac conditions are the major risk factors for stroke in Saudi Arabia. Transient ischaemic attacks and smoking were also reported in the literature as being risk factors for stroke (Alrajeh, Awada, Niazi, & Larbi, 1993; El Sayed, Adeuja, El-Nahrawy, & Olaish, 1999; Qari, 2001; Robert & Zamzami, 2014). Stroke prevalence and incidence studies are limited; the only available ones are hospital-based, which shows that stroke epidemiology has not been studied at a national level. Regarding aphasia, there is no evidence in the literature of current studies that have investigated epidemiology in Saudi Arabia.

In the retrospective study of Alrajeh, Awada, Niazi, and Larbi (1993), records of 500 Saudi stroke patients admitted to King Fahad National Guard Hospital in Riyadh from December 1982 to June 1992 were reviewed. The researchers concluded that the annual incidence rate was 43.8 per 100,000, the mean age was 63±17 years, and the male-to-female ratio was 2.2:1. In another epidemiological study, Qari (2001) reviewed the records of 71 Saudi and non-Saudi stroke patients admitted to King Abdulaziz University Hospital from January 1997 to January 2000. The researcher concluded that the incidence of stroke comprised 3% of the total medical admissions during the time of the study, the mean age was 63 years, and the male-to-female ratio was 3.4:1. In addition, Qari (2001) reported that 32% of stroke patients had aphasia when they were admitted to the hospital. In a different prospective hospital-based study, El Sayed, Adeuja, El-Nahrawy, and Olaish (1999) studied the characteristics of stroke in 329 Saudi patients admitted in two years to King Fahad Hospital, Hofuf, in the Eastern Province of Saudi Arabia. The researcher reported that the male-to-female stroke ratio for all stroke types was 1:1 (except for haemorrhagic strokes, for which the ratio was 2.1:1), with the mean age being 62.8±11.1 years for males and 59.6±15.4 years for females.

In both developed and developing countries there is an increase in the number of the elderly in the population (Robert & Zamzami, 2014). Al-Jadid and Robert (2010) and Al-Eithan, Amin, and Robert (2011) reported in their studies that stroke in Saudi Arabia occurs more in the age group of 61–70 than in the age groups of 20–30 and 30–40, which is in line with other studies in the literature that reported that stroke prevalence increases with age in Western societies (Saposnik & Black, 2009; Saposnik et al., 2008).

In their systematic review, Appelros, Stegmayr, and Terént (2009) reported that, worldwide, stroke occurs more commonly in males than in females. In Saudi Arabia a similar pattern of a higher male-to-female stroke ratio was found in studies including Alrajeh et al. (1993), Qari (2001) and Yaqub, Shamena, Kolawole, and Patel (1991). In the study conducted by El Sayed, Adeuja, El-Nahrawy, and Olaish (1999) the equal male-to-female stroke ratio was not similar to that observed in the other two studies. The equal ratio was not explained in their study; however, this could be attributed to the fact that the study was hospital-based and that data from other hospitals in the same area were not included. This indicates the presence of data from other hospitals in Saudi Arabia and small towns that were not yet captured, which stresses the need for a stroke register in different regions in Saudi Arabia, as suggested by El Sayed, Adeuja, El-Nahrawy, and Olaish (1999).

From the abovementioned studies it can be noticed that the approximate mean age of stroke in Saudi Arabia is 63 years, with males being more affected than females. To compare with UK data, males in the UK are also more affected by stroke than females, whereas the average age of stroke in the UK is higher than Saudi Arabia (72 for makes and 78 for females) (Royal College of Physicians & Sentinel Stroke National Audit Programme (SSNAP), 2017).

It can be concluded that there is a need for updated published research into stroke epidemiology and characteristics in Saudi Arabia, and that available information was derived from patients admitted to hospitals in major cities. There is also a lack of research into aphasia epidemiology in Saudi Arabia.

1.5.2 Medical and rehabilitation services

In Saudi Arabia, the Ministry of Health (MOH) is the main provider of health services. According to the Ministry of Health (2018), the total number of MOH hospitals is 284 with 43,680 beds. Healthcare services provided by MOH facilities are restricted to Saudis, due to which, in addition to population growth, the increased number of inpatients in MOH facilities, and the financial burden on the MOH, there was a need for growth in the private sector. The Ministry of Health (2018) reported that the number of private sector hospitals reached 163, and that the number of polyclinics is 2922 with the majority located in Riyadh and Jeddah. In addition to the MOH and the private sector, certain organisations provide healthcare services to their employees in Saudi Arabia, including the National Guard (Colliers, 2017). The Ministry of Health (2018) reported that the total number of MOH, other governmental sector, and private sector hospitals is 494. Recently, and in order to achieve the aims of “Saudi Vision 2030” (the Saudi Arabia’s future economic and social vision), the Saudi healthcare system has been moving towards privatising healthcare services, increasing the partnership between the private and public sectors, initiating new domestic healthcare programmes and increasing the Saudi professional workforce (Shearman & Sterling LLP, 2016).

According to the World Health Organization (WHO) (2013), the national strategy in Saudi Arabia for primary healthcare and service delivery is person-centred, wherein health promotion and protection in addition to social factors are considered. The Saudi MOH and the WHO have identified strategic priorities in the healthcare system that emphasise the person-centred and integrated service delivery approach in which the partnership between stakeholders is promoted.

In a study that was conducted in Saudi Arabia in order to understand patients' awareness of their rights, the majority of respondents expressed that they were unaware of the patients' bill of rights published by the Saudi MOH and their right to be informed about their diagnosis and treatment plan (Almoajel, 2012). In a systematic review that was conducted by Almutairi and Moussa (2014) in order to explore the quality of healthcare services in Saudi Arabia, the researchers concluded that the quality of healthcare services has improved over the years (1970 to 2009); however, some issues continue to emerge. Almutairi and Moussa (2014) categorised factors that influence the quality of healthcare services into patients' factors (health literacy, access to care, and culture) and providers' factors (medical care, workload, culture, and job satisfaction). The researchers expressed that the relationship between healthcare professionals and patients has a great impact on the quality of services and the outcome. Moreover, Almutairi and Moussa (2014) reported that patients wanted to be part of decision making; however, the majority of patients are unaware of their rights. Thus, communication between patients and healthcare professionals is needed so as to enhance the quality of services.

In Saudi Arabia, medical rehabilitation centres were not introduced until the early years of the 21st century, as they were included in MOH facilities. Before that time the government had some prosthesis centres in some hospitals, the Ministry of Defence and Aviation launched rehabilitation centres in military hospitals, and some private hospitals provided rehabilitation beds to people who had disabilities due to work accidents (Al Jadid, 2011). Nowadays, there are separate rehabilitation centres, albeit mainly concentrated in large cities, that provide services to adults and children, including Sultan Bin Abdulaziz Humanitarian City (Riyadh), the Rehabilitation Unit of King Abdulaziz Medical City (Riyadh), the Rehabilitation Hospital of King Fahad Medical City (Riyadh), and the Rehabilitation Hospital of Al-Hada Military Hospital (Taif). According to the Ministry of Health (2018), the total number of MOH rehabilitation centres is 14, whereas the total number of private sector physiotherapy/rehabilitation centres is 167 as reported by the Saudi General Authority for Statistics (2018). However, there remains a constant need for more rehabilitation centres in Saudi Arabia due to the increase in population and in road accidents, in addition to changes in lifestyle that cause health issues including diabetes and stroke (Al Jadid, 2011; WHO, 2013).

Stroke rehabilitation includes services that aid patients with stroke in order to enhance their quality of life by improving their physical, psychosocial and vocational skills while considering physiological and environmental factors (Bindawas & Vennu, 2016). As Bindawas and Vennu (2016) reported, stroke rehabilitation services in general could be provided in different settings, including inpatient settings, outpatient settings, nursing facilities, and home-based services.

As viewed by neurologists and the Saudi Arabian Ministry of Health's stroke committee, stroke care in Saudi Arabia requires a plan for progress (Al-Senani et al., 2019; Al Khathaami et al., 2011). Al Khathaami et al. (2011) stressed the need to establish more stroke units, raising public awareness and training healthcare professionals. Moreover, Bindawas and Vennu (2016) reported in their report that stroke rehabilitation programmes in Saudi Arabia need to be enhanced. The researchers provided some recommendations for rehabilitation professionals and policymakers, including intensive stroke educational topics in the curriculum of healthcare professionals, post-professional programmes, continuing education, establishing an evidence-based national framework with which to support decision making for complex health issues, increasing stroke research funding opportunities, improving accessibility of healthcare facilities and establishing guidelines for healthcare professionals on stroke care at different stages. Aiming to enhance stroke services in Saudi Arabia, Al-Senani et al. (2019) conducted a health economic analysis of the development of stroke care in Saudi Arabia. In comparison to the current stroke care services, the researchers concluded that the development of stroke care in Saudi Arabia could facilitate improvement in patient outcomes and also lower overall costs.

After providing background information on stroke and aphasia within the research context of Saudi Arabia, the following section presents an overview of methodologies that researchers have adopted to study aphasia, as evidenced in the research literature.

1.6 Aphasia and research methodologies

In aphasiology, quantitative methods, including utilising standardised testing procedures and analysing relationships statistically, have been adopted to study topics including linguistic aspects of aphasia (e.g. Bastiaanse & Jonkers, 1998; Lee, Yoshida, & Thompson, 2015), the efficacy of intervention approaches (e.g. Hinckley & Carr, 2005; Mozeiko, Coelho, & Myers, 2016), the validity of testing measures (e.g. Marshall & Wright, 2007; Wilshire, Lukkien, & Burmester, 2014), and the correlation between lesion sites and language deficits through the use of neuroimaging technologies (e.g. Kümmerer et al., 2013; Mummery, Ashburner, Scott, & Wise, 1999). Quantitative research into aphasia forms a large body of literature with multi-disciplinary contributions addressing a wide range of research questions relating mainly to language representation and language processing.

Health care models have been described in the literature as medical and social. In the medical model, the illness or disorder within the person is the focus of treatment, while in the social model, the dynamic of the interaction between personal, physical, environmental, and societal factors is considered (Elman, 2016). The social model was applied to disability in 1970s (Elman, 2016), and in 2001, the World Health organisation developed The International Classification of Functioning, Disability and Health (ICF) framework that facilitates describing human's disability and function from a medical and social perspectives (World Health Organization, 2001). With the growing influence of the ICF framework in the field of speech and language therapy, and the move from a medical model to a more social model of health, researchers and clinicians have become more interested in exploring the experience of living with aphasia from different perspectives including that of the PWA and family members, and also of the professionals working with the PWA, rather than focusing solely on the nature of the language impairment as has largely been the case with quantitative research in aphasia. This type of study which seeks to uncover the views and reactions of the participants does not lend itself to quantitative methods; therefore, more studies that adopted qualitative methodologies have been undertaken with PWA in recent years. Qualitative methods were used to explore the broad context of individuals' lives that influences their health conditions; for example, living successfully with aphasia (Brown, Worrall, Davidson, & Howe, 2011a & b, 2012; Cruice, Worrall, & Hickson, 2006; Grohn, Worrall, Simmons-Mackie, & Hudson, 2014), functional communication (Holland, 1982; Holland, 1991; Hopper, Holland, & Rewega, 2002), impact of aphasia according to the ICF framework (Grawburg, Howe, Worrall, & Scarinci, 2014; Matos, Jesus, & Cruice, 2014; Threats, 2010), and social participation (Elman, 2006, 2016). The following section presents an overview of qualitative research methodology and methods used in this type of research.

1.7 Qualitative research methodology

Qualitative research attempts to explore people's experiences and investigate phenomena by studying events that occur in their natural, social contexts (Creswell, 2007; Flick, 2014; Sanders, 2010). In this kind of research, hypotheses are usually formulated after analysing data, rather than being developed first, as is common to quantitative research (Silverman, 2011). Deciding upon whether to use a qualitative or quantitative method highly depends on the research aim and the question being asked by the researcher, e.g. measuring a behaviour would lead to quantitative research, while exploring why it was exhibited would be best approached via qualitative methods (Richards, 2005). Ritchie et al. (2014) argued that a thorough definition of *qualitative research* might be difficult to present because of the different philosophical concepts and approaches that it involves. In the following sub-sections, these main aspects and approaches are discussed to provide an outline of the methods and issues relevant to the background of qualitative research. Information on research design, data collection, data analysis, and research rigour are presented before discussing their application to aphasia research.

1.7.1 Philosophical aspects underpinning qualitative research

To achieve a comprehensive understanding of qualitative research it is necessary to reflect on how this kind of research emerged. Debates were presented and questions were proposed as to the most appropriate ways in which to study social issues that involve human behaviours, communication, beliefs and views of individuals. These debates focused on two aspects in philosophy: ontology and epistemology (Ritchie et al., 2014).

Ontology is a philosophical school that focuses on reality and the world. The main focal points of ontology comprise the possible existence of multiple realities and whether there is an independent reality that is separate from people's thoughts and perceptions (Creswell, 2007). As a result of the reality debate, two philosophical positions have emerged: realism and idealism. Realism supports the idea of the presence of a reality that is distinct and independent from people's thoughts and understanding, while idealism argues that reality is dependent on people's own minds and perceptions (Smith, 1983).

The second philosophical aspect, epistemology, is related to the view and understanding of how knowledge is acquired (Mack, 2010). In addition, epistemology is concerned with the researcher's role and engagement in the research (Creswell, 2007). In epistemology, debates were presented as to whether knowledge is acquired inductively or deductively by researchers. In the inductive (bottom-up) view the process of knowledge acquisition starts with observing and collecting information in order to develop a theory. In contrast, deductive (top-down) theory proposes that theories are developed at first, and then information is collected so as to support them (Bowling, 2014).

Within epistemology, another two philosophical positions have emerged: positivism and interpretivism. Positivist scientists believe that research should be conducted through direct experiences rather than through conceptual predictions (Crotty, 1998). Positivism proposes that a topic should be investigated in an objective manner through a systematic and standard procedure, and that it is convenient to use natural science methods to study a social phenomenon (Bowling, 2014; Ponterotto, 2005). In contrast, interpretivists believe in using methods that capture real-life experiences, and argue that natural science approaches are not suitable for studying social science because people's views, experiences and thoughts are essential elements in social research (Ponterotto, 2005; Ritchie et al., 2014). In addition, interpretivism claims that it is necessary to have a good understanding of the research context when collecting and analysing data, whereas this is not as important in positivism (Willis, 2007).

These philosophical arguments have directed researchers towards adopting specific philosophical stands according to their own views, aims and research backgrounds. Since qualitative research aims to explore peoples’ views, understanding, and interpretations around a certain phenomenon, then it assumes that reality is constructed (Symon & Cassell, 2012). Hence, adopting tools to collect in-depth data about views and experiences, in addition to highlighting the research context are required in qualitative research.

1.7.2 Qualitative research approaches

During the 20th century, qualitative research started to be commonly used amongst social science researchers (Ritchie et al., 2014), and different approaches were developed. Creswell (2007) provided an overview of the different approaches to qual research, identifying five main forms of research which are as follows: ethnography, phenomenology, grounded theory, narrative research, and case studies.

Ethnography is the study of people and their cultures (Creswell, 2007). This kind of research was developed and has been commonly used within the fields of anthropology and sociology (Seale, 2004). In ethnography the researcher needs to be involved within a culture so as to report upon and analyse behaviour, beliefs, language, and life routines (Denscombe, 2003). When conducting such a study the researcher usually collects data through taking notes, making observations and conducting interviews. Thereafter, data are analysed via a descriptive process, and themes are created. Finally, the researcher develops a written report in order to present a detailed description of the culture being studied (Creswell, 2007).

Phenomenology is a school of research concerned with the study of a certain phenomenon that is experienced or presented amongst a group of people (Creswell, 2003). This kind of research was developed from the disciplines of philosophy, psychology and education (Creswell, 2007). In phenomenology the researcher studies and provides detailed explanations of people's true experiences, rather than describing abstract concepts or theories (Denscombe, 2003). The researcher collects data via interviewing participants and making observations. Thereafter, data are analysed so as to extract significant statements (sentences that highlight people's experiences) and themes. Finally, the researcher provides a written report that describes the phenomenon in detail based on the views of insiders (Creswell, 2007).

Grounded theory is a research approach that aims to generate a theory based on people's experiences or views regarding a certain phenomenon (Corbin, 2011). This kind of research emerged from the field of sociology (Creswell, 2007). When adopting the grounded theory approach the researcher uses data collection methods including unstructured interviews, open-ended questions, and field notes in order to collect data that are not influenced by a previously assumed theory (Denscombe, 2003). Then, the researcher starts the analytical process by categorising and coding the data collected. Ultimately, a theory is generated and reported (Creswell, 2007).

Narrative research is based on telling the stories of people and their lives (Robson & McCartan, 2016). This approach was developed from the disciplines of sociology, anthropology, history and psychology. In this narrative approach the researcher collects stories from one or more individuals by conducting interviews. Thereafter, these stories are analysed, categorised into frameworks and retold by the researcher in chronological order (Creswell, 2007).

Case study research is a method that aims to build a deep understanding of a specific case, rather than developing a theory; the case could be a single person, a specific group of people, or an action (Denzin & Lincoln, 2008). Case studies emerged and have been commonly adopted in the fields of psychology, law, political science, and medicine. The researcher collects data via observing and interviewing participants. Then, data are described and analysed at a general level or for a specific area in the case. In the presence of multiple cases the researcher has the choice of describing each case individually and then comparing themes and descriptions with those of other cases (Creswell, 2007).

Choosing a research approach depends on many factors, including the research aims, proposed questions, and context (Ritchie et al., 2014). For example, when a researcher aims to explore participants' experience with a medical condition in their natural home environment, phenomenology could be the most appropriate approach to address this topic.

1.7.3 Designing qualitative research

When conducting qualitative research, planning ahead and spending time constructing the design are necessary in order to produce robust, high-quality research. Designing a qualitative research project constitutes setting a plan in respect of how the study will be conducted (Berg, 2006). Thus, research elements, including the research question and aim, sampling, ethics, data collection method, and data analysis method, need to be planned carefully. Moreover, research rigour needs to be ensured in all aforementioned aspects. The following sub-sections provide an overview of these elements and present different options.

1.7.3.1 Research question and aim

The research question in a qualitative study functions as a guide for the researcher throughout the entire project (Hennink, 2011). It is recommended to propose one or two central questions and then extract sub-questions in order to provide a more detailed perspective (Creswell, 2009). In addition, the central question needs to reflect the research approach in the way in which it is phrased and in the verbs used. For example, if the researcher is adopting the grounded theory approach, the research question must be phrased in such a way as to allow for theory formulation; words including “discover” might be used. Because qualitative research aims to explore and discover, the researcher needs to take into consideration that questions might be refined during the study as unexpected matters arise (Creswell, 2009).

1.7.3.2 Subject recruitment and sampling

Hennink (2011) proposed that this process of asking participants within the population to participate in the study (subject recruitment) mainly contains two phases. These phases include defining the target population for the specific topic being investigated, and then choosing a recruitment strategy. The researcher can recruit subjects in qualitative studies by conducting one of the five commonly used strategies: seeking assistance from a recognised member of the community (gatekeepers), recruiting subjects from gathering events (networks), recruiting by asking subjects if they know someone who meets the research criteria (snowballing), advertising in newspapers (advertisement), or inviting subjects who have already participated in a quantitative part of a study to participate in the qualitative part (research-based recruitment) (Hennink, 2011; Oppong, 2013).

In general, the number of participants in qualitative research is relatively small when compared to quantitative studies (Ritchie et al., 2014). This is related to the in-depth analysis and interpretation of cases that are usually conducted in qualitative research. For example, and in relation to aphasia research, Breitenstein et al. (2017), de Jong-Hagelstein et al. (2011) and Humphreys, Thomas, Phillips, and Lincoln (2015) conducted quantitative aphasia randomised controlled trials and the number of participants recruited in their studies ranged between 80 and 158. In contrast, Wood, Connelly, and Maly (2010), Johansson, Carlsson, and Sonnander (2012) and Brown, Worrall, Davidson, and Howe (2011a & b) conducted qualitative studies to explore topics in aphasia and the number of participants in their studies ranged between 10 and 25.

Sampling in qualitative research could take different composition types, including maximum variation (subjects who differ from one another across a set of pre-determined criteria), homogeneous sampling (subjects who are similar to one another), extreme case (special cases for the topic including individuals who did not experience what the majority has), stratified purposeful (groups that have variations but are homogeneous at some level), and critical case (important cases for the topic) (Flick, 2014; Ritchie et al., 2014). Creswell (2007) proposed an appropriate sampling method for each qualitative approach. He stated that in grounded theory, for example, the researcher might start with a homogeneous sample so as to develop a theory, and then recruit a heterogeneous one in order to prove or disprove the theory.

Unlike quantitative research, random sampling might not be the most appropriate method in qualitative studies. Thus, subjects in qualitative research are usually selected purposefully and systematically based on their experiences and on specific criteria justified by the researcher (Flick, 2008a; Hennink, 2011). To provide one example from the aphasia literature, Worrall et al. (2011) reported using maximum variation sampling to obtain a variety of views on therapeutic goals from PWA, and variation within the sample was based on gender, age, time post onset of stroke, and aphasia severity.

Furfey (1947) indicated that sampling is a challenging process, and difficulties could be encountered in finding an adequate sample with which to investigate a certain topic. Oppong (2013) stressed the difficulty of including all cases that experience a certain phenomenon in qualitative research, leading the researcher to select a certain number as a sample and imposing some bias upon the research. As Groger, Mayberry, and Straker (1999) reported, other difficulties could arise in obtaining approval from the target facilities and in accessing the candidate participants. Tuckett (2004) stated that a challenge is encountered also when participants withdraw from the study, die or cannot be traced.

To overcome some sampling problems, Greene and McClintock (1985) and Tuckett (2004) suggested to use alternative methods for data collection in order to minimise sampling bias and increase rigour. To overcome problems related to the withdrawal of participants, Tuckett (2004) suggested the adoption of different data collection techniques so that the research design is not dependent on one method. To address challenges related to site approval, Devers and Frankel (2000) suggested reaching out to social networks to build professional relationships that would facilitate access to sites and participants.

1.7.3.3 Ethical considerations

For all research projects the institution review board or the ethics committee must assess the project so as to ensure that it will be conducted in an ethical manner (Hennink, 2011). Thus, it is essential for the researcher to ensure that the project is following ethical standards in all of its different stages (preparation, conduction and dissemination) (Flick, 2008a). Hennink (2011) argued that ethical considerations are more highlighted and pointed out in qualitative research for two reasons: qualitative studies usually aim to understand sensitive issues, e.g. violence, and also aim to achieve a deep exploration of people's feelings, beliefs and experiences.

According to Hennink (2011) and Israel (2006), five major ethical concepts must be taken into consideration when designing and conducting a qualitative study: informed consent, confidentiality, avoiding harm, anonymity, justice, and beneficence. Issues related to the five concepts reported might arise at any stage of the study. For example, while conducting a focus group in the data collection stage the researcher might risk the confidentiality of a participant when a sensitive topic is discussed with other group members (Ritchie et al., 2014). Thus, it is highly important for researchers to be aware of ethical issues that they might encounter during all of the stages of research, so that they can anticipate, avoid and resolve them.

1.7.3.4 Data collection

For all kinds of research it is necessary to understand how data will be collected and organised before starting the process to avoid problems arising in later stages because of a lack of planning, including collecting data that are not suitable or rich enough to be analysed (Berg, 2006). Data in qualitative research can be collected using the following methods: interviews, focus groups, observation, questionnaires, documents and audio-visual materials.

1.7.3.4.1 Interviews

In qualitative research, interviews are usually used with participants to collect deep information about the topic under investigation. Creswell (2007) provided some general guidelines for researchers in respect of conducting interviews. Firstly, the researcher needs to identify the subjects through the process of sampling. Then, the researcher needs to identify the most appropriate interviewing type for the specific research, i.e. via the phone, as a focus group, or one-to-one. The decision depends on factors including accessibility, time limitations, and the characteristics of participants. Qualitative interviews could also be structured (following a strict protocol), semi-structured (following a protocol but enabling flexibility) or unstructured (Corbin & Strauss, 2014). Silverman (2013) encouraged developing an interview guide that contains prepared questions so as to guide the researcher during the interview and add a level of standardisation to the research. Furthermore, researchers must take some preparation into consideration, including site and participants’ approval and scheduling the interview appointments (Robson & McCartan, 2016).

Preparing questions is a fundamental procedure in interviewing. Robson and McCartan (2016) stated that questions used in interviews could take three main forms: closed, open and scale. Questions could be open, allowing the researcher to elicit a more elaborate response from participants, e.g. “What happened when you were there?”. Closed questions, however, are phrased in such a way as to force participants to choose from specific options, including yes/no questions, e.g. “Have you travelled before?”. Scale items could be labelled under closed questions, and may not be in the form of a question, e.g. “The workshop increased my knowledge: agree, neutral, disagree”.

Probes and prompts are other types of questions that could be used by the researcher during the interview. Probe questions are asked by the researcher in order to clarify an issue that has been discussed previously or expand on an answer that has been given, while prompts are asked so as to gain a better understanding of an issue that has not been raised previously; alternatively, they are used to provide some options (Ritchie et al., 2014; Robson & McCartan, 2016). The researcher needs to be careful not to use leading questions that encourage the participant to respond in a specific way, including asking, “Were you sad when that happened?” (Ritchie et al., 2014).

When conducting interviews, the researcher needs to master and demonstrate certain professional and personal skills. These include good listening skills and building trust with participants (Marshall, 2011). Furthermore, researchers are encouraged to practise interviewing beforehand and receive feedback on their performance (Robson & McCartan, 2016).

In-depth interviewing is a type of data collection in which the researcher conducts a one-to-one interview in order to understand the individual's experiences, thoughts and perspectives (Hennink, 2011). The purpose behind conducting in-depth interviews is to collect deep and thorough information on the topic. In-depth interviews must have a structure in which a protocol or schedule is used, and must also be flexible enough to allow for a deep understanding. Moreover, in-depth interviews need to be interactive so that new knowledge and information could emerge (Ritchie et al., 2014). Gaskell (2000) reported that interviews start with introducing the project, thanking participants for attending, and informing them of audio or video recording. Thereafter, the interview starts and continues to cover deeper areas within the topic. Finally, the researcher ends the interview, thanks participants, allows for questions and ensures confidentiality.

1.7.3.4.2 Focus groups

In qualitative research, focus groups is another data collection method. Conducting focus group sessions to collect data from participants is a method that was adopted from marketing research (Marshall, 2011). In focus groups the researcher recruits six to eight participants who share similar characteristics that are relevant to the research topic. Then, participants discuss issues raised by the researcher while the researcher leads the session, which takes 60–90 minutes (Hennink, 2011). The number of participants and the amount of time of a session could vary depending on the research topic and the population (Ritchie et al., 2014). In a focus group session, five stages usually occur: general introduction and rule setting, participants' introduction, topic introduction, discussions, and closing the session (Ritchie et al., 2014).

It is the researcher's responsibility to create a comfortable environment in which participants can answer questions, discuss ideas and share their experiences and feelings (Marshall, 2011). To record data in focus groups the researcher could videotape and audiotape the session for future analysis (Marshall, 2011). It is recommended that the researcher use a pre-developed discussion guide in order to lead the session smoothly (Hennink, 2011). While a focus group is a convenient method for exploring a topic and understanding different views, the researcher should take into consideration that this method is not suitable for collecting personal perspectives. This is due to the group environment and the lack of confidentiality when discussing sensitive and personal issues with a group of people (Hennink, 2011).

1.7.3.4.3 Observations

Observation is commonly used in qualitative research. In observation the researcher aims to understand participants' interactions in their social settings (Marshall, 2011). Thus, the researcher systematically observes and records the actions, body language, and behaviour of participants in their environments (Hennink, 2011).

In observation, recording behaviour could be accomplished by using a pre-developed checklist that aims to examine specific aspects (Marshall, 2011). Moreover, recording naturally occurring events by using field notes is a well-known method through which to record observations (Silverman, 2013). Field notes are detailed and objective descriptions of what is being observed. However, the researcher should take into consideration that the process of taking field notes must be systematically planned and managed carefully so as to produce notes that are usable for analysis (Marshall, 2011).

1.7.3.4.4 Questionnaires

Questionnaires are commonly used by researchers because they are cost-effective. In addition, questionnaires are considered easier to manage than interviews (Denscombe, 2003). However, there are some disadvantages related to designing and using them. The pre-coded answer choices in a questionnaire might not be comprehensive in that they cover a wide range of choices. This could force participants to select a choice that does not represent their perspective on an issue, which could then influence the trustworthiness of the research. In addition, the order and wording of questions might not be designed to be suitable for all participants targeted (Bowling, 2014).

Questionnaires should be able to collect data that are appropriate for analysis. Furthermore, they should contain straightforward questions that are related to the topic studied. When designing a questionnaire the following types of questions could be used: lists, statements, yes/no, agree/disagree, ranking, choosing, rating, degree of agreement, and feelings (Denscombe, 2003).

1.7.3.4.5 Documents and audio-visual materials

Documents and audio-visual materials could be used alone, or as secondary sources of data when combined with the aforementioned collection methods (Marshall, 2011). Documents could be public, e.g. newspapers or official letters, or personal, e.g. journals or emails. Audio-visual materials could take the form of films, pictures, art objects, or computer applications (Creswell, 2009).

Choosing a method could be challenging for beginner researchers. Creswell (2007) argued that choosing the appropriate method highly depends on the research approach and the unit of analysis. For example, in grounded theory and phenomenological studies, interviews could elicit an appropriate amount and quality of data, while in ethnographic studies, conducting observations and interviews together could be the best solution. Regarding the unit of analysis, the researcher in grounded theory and phenomenological studies needs to explore the views of a small number of individuals, whereas in ethnologic studies the researcher usually needs to study an entire culture.

1.7.3.5 Data analysis

After collecting the qualitative data required, the researcher starts to prepare the data for analysis. It is recommended that all raw data be in the same format, e.g. a Word document, and each part be coded or identified in some way. Moreover, it is recommended that the researcher leave a margin when raw data are collected so that comments can be added later during the phase of analysis (Denscombe, 2003). In general, the process of data analysis starts with data organisation, followed by reading and adding notes, coding and labelling, describing and creating themes, interpreting, and presenting data (Creswell, 2007, 2009).

Data organisation usually starts with transcribing recorded interviews or focus groups. Deciding on the degree of detail while transcribing data highly depends on the purpose of the study. The majority of researchers in qualitative studies need to transcribe words exactly as they were said in the setting for the purpose of their studies. This could be challenging due to the natural features of continuous speech, including pauses, repetitions, and verbal tics, e.g. “um”. Data could be transcribed using different styles, including transcribing core information, verbatim transcription, verbatim with dialect, and transcription at the discourse level, e.g. stresses and hesitations (Gibbs, 2007).

In qualitative research it is the researcher’s role to adopt the most appropriate method for the research topic and aim. There are general analytical approaches that are well known in the field of qualitative research, including narrative analysis, discourse analysis, content analysis, grounded theory, and thematic analysis (Flick, 2014; Ritchie et al., 2014).

Narrative analysis aims to extract a story from the participant’s experience and then interpret it in order to find deeper aspects including intentions and meanings (Riessman, 2008). Discourse analysis aims to analyse the use of language in a specific population or a certain context with regard to structure and function (Harper & Thompson, 2011).

Content analysis has been previously used to describe and quantify the explicit content of communication (Berelson, 1971). Over time, researchers started to use the method of content analysis to study implicit content and develop themes as well (Graneheim & Lundman, 2004). In content analysis, units of analysis including phrases or paragraphs are assigned codes based on the meaning of the unit; thereafter, codes are categorised according to certain commonalities (Graneheim & Lundman, 2004). Underlying meanings are then discovered and themes are extracted for further interpretation (Graneheim & Lundman, 2004). Content analysis can be “conventional” in which codes derived from data, “directed” in which codes derived from theories, or “summative” in which codes derived from own interest or literature (Hsieh & Shannon, 2005).

Grounded theory is a method of qualitative data analysis that was developed by the researchers Barney Glaser and Anselm Strauss (Glaser & Strauss, 1967). In their approach of grounded theory, a systematic procedure of coding is followed in order to develop a thematic structure of categories and theoretical concepts that leads to novel theory development (Glaser, 1999). Coding in grounded theory involves three overlapping stages: open coding, axial coding and selective coding. In the first coding stage, i.e. open coding, segments of text are coded. Such open coding could be applied at different levels of detail including line by line or paragraph by paragraph. Then, relationships are identified amongst the assigned open codes so as to refine and categorise them, thereby forming axial codes. In the selective coding stage, a higher level of conceptualisation is applied and a core category is searched for in data (Flick, 2006).

The application of grounded theory involves core methodological strategies. Searching for core concepts, memo writing, theoretical sampling, and simultaneous data analysis and collection, in addition to constant comparisons, are key methodological features of grounded theory. Skeat and Perry (2008) argued that selective coding or finding conceptual categories in data could be confused with descriptive categories for researchers beginning to utilise grounded theory. As Glaser (2002) described, a concept is a latent structure that emerges after searching for patterns in data, rather than direct descriptions as in open codes or categorical relationships as in axial coding. Memo writing is a strategy used in qualitative research to facilitate thinking in respect of the area being investigated, abstraction of the topic, and progress of the study (Birks, Chapman, & Francis, 2008). Memos were classified in the literature of grounded theory research as coding, operational and theoretical memos (Strauss, 1998). Birks, Chapman, and Francis (2008) claimed that classifying memos into coding, operational and analytical memos was more convenient, as it added a greater breadth with regard to the stages of analysis. Writing coding memos allows researchers to store information on how coding evolved and how they were flexible in responding to new data. Operational memos enable researchers to store information on decision making and on justifications regarding decisions made during the different phases of the study. Analytical memos allow researchers to think about data at a higher level of abstraction and examine theories and concepts (Birks, Chapman, & Francis, 2008).Theoretical sampling is a process in which data collection, analysis and interpretation are conducted simultaneously and in a cyclical manner until a point of saturation at which no new data are emerging. In theoretical sampling, researchers recruit new participants once new categories emerge, while analysing data in order to deeply investigate the phenomenon and develop a theory (Charmaz, 2006). In constant comparison, simultaneous coding and analytical thinking are applied in order to identify relationships, theoretical concepts, and patterns in data (Glaser, 1999; Pope, Ziebland, & Mays, 2006). By adopting this technique, coded data units are continuously compared to other units and categories. Furthermore, categories are continuously compared for their properties, refined and integrated (Glaser, 1999). This cyclical analysis allows for codes and themes to be constantly refined, wherein new emerging codes are constantly searched for in new data, grouped together or collapsed.

Thematic analysis is a systematic process of coding data and identifying patterns of meaning that are to be further interpreted. The systematic analysis approach is known for its flexibility in terms of the theoretical framework, research question, and data collection methods (Clarke & Braun, 2017). In thematic analysis, themes are examined deeply as they are identified from data, interpreted, and reported in detail (Harper & Thompson, 2011). Thematic analysis could be seen as a broad term for different approaches reported in the literature including the general inductive method (Thomas, 2006), Braun and Clarke’s thematic analysis (Braun & Clarke, 2006), framework analysis (Richie, Spencer, & O’Connor, 2003), and Flick’s thematic coding (Flick, 2014). In thematic analysis, researchers immerse themselves in the data by reading and reflecting. Researchers then assign codes to data units including phrases and paragraphs, and extract themes. Thematic analysis can be descriptive, e.g. when researchers describe emergent themes. Thematic analysis could go beyond descriptions to theme interpretation, explanation and reflection (Braun & Clarke, 2006; Flick, 2014; Smith & Firth, 2011; Thomas, 2006).

During the process of data analysis, computer-assisted qualitative data analysis software (CAQDAS) programs can be used to aid researchers. These programs allow the researcher to store, file, search for and code qualitative data (Silverman, 2013). However, these programs do not analyse data that have been entered. Silverman (2013) stated that CAQDAS programs provide the researcher with the advantage of saving time while handling a large amount of qualitative data, in addition to enhancing the rigour of analysis and data management. Some of the available CAQDAS programs include MAXqda, QSR NVivo, ATLAS.ti, and HyperRESEARCH (Creswell, 2009).

1.7.4 Research rigour

There have been major discussions in the literature surrounding how qualitative research should be evaluated on its robustness (Flick, 2008a, 2008b; Sanders, 2010). Validity and reliability are two major concepts when referring to research quality. Validity in qualitative research refers to the accuracy of the method in detecting the truth (Gibbs, 2007), while reliability is related to the consistency of the analytical procedure (Noble & Smith, 2015).

In qualitative research literature the concept of *trustworthiness* is commonly used to judge research rigour. Lincoln and Guba (1985) proposed four main criteria for evaluating research trustworthiness, namely credibility, transferability, dependability and confirmability. Credibility is related to validity and detecting the truth, transferability is related to the generalisability of results, dependability is related to reliability and consistency, and confirmability is related to objectivity (Shenton, 2004).

Gibbs (2007) and Shenton (2004) proposed different strategies that ensure trustworthiness and promote high standards in all qualitative research stages. One of the proposed strategies with which to enhance research credibility is that of data triangulation, wherein data collected using different methods or from different researchers are compared. Another proposed method is that of constant comparisons, wherein the accuracy and consistency of codes are constantly examined, in addition to the searching of differences and variations in coded events. To promote research dependability, Gibbs (2007) and Shenton (2004) reported strategies including in-depth methodological description, checking transcriptions so as to ensure that they are free of mistakes, and crosschecking codes with other researchers. Shenton (2004) reported that research transferability and confirmability could be enhanced in qualitative research by providing a detailed description of the background, context and phenomenon in order to allow readers to examine its applicability. Moreover, they suggested data triangulation, as well as admission of the researcher's view and the research limitations so as to reduce bias and enhance objectivity.

After presenting an overview of qualitative research in general, the following section discusses qualitative research in stroke and aphasia literature.

1.8 Qualitative methods used in stroke and aphasia research

The following sub-sections present an overview of topics and qualitative approaches used in aphasia research, in addition to data collection and analysis methods in stroke and aphasia research. Moreover, strength and limitations of qualitative research in the field of aphasia, and aphasia studies in the Saudi context are discussed.

1.8.1 Overview of research topics and approaches

Damico and Simmons-Mackie (2003) argued that qualitative research is a valuable tool in the discipline of speech and language pathology because of its characteristics. They reported that the first feature of qualitative research was the alignment between its purpose (investigating social events) and the focus of speech and language pathology (human communication). The second feature involved authenticity and context-oriented data collection and analysis methods. The third and fourth features constituted the systematic data collection methods and the descriptive nature of the results, respectively (Damico and Simmons-Mackie, 2003).

Qualitative studies in aphasiology have focused on understanding people's views and their reactions towards certain issues or events through the adoption of methods including interviews and observation. As reported by Simmons-Mackie and Lynch (2013), topics of qualitative aphasia studies in the literature included experience of aphasia (Armstrong, Hersh, Hayward, Fraser, & Brown, 2012; Jones, Mandy, & Partridge, 2008), activities and participation (Ashton et al., 2008; Davidson, Worrall, & Hickson, 2003), and intervention or services (Pound, Parr, & Duchan, 2001; Wade, Mortley, & Enderby, 2003). Qualitative studies on aphasia have also been conducted to investigate therapeutic goals and needs as stated by Simmons-Mackie and Lynch (2013). In relation to the area of therapeutic goals, the literature on stroke and aphasia shows that views of stakeholders have been explored in different countries including Australia (Hersh et al., 2012a; Howe et al., 2012a; Rohde et al., 2012a; Sherratt et al., 2011; Worrall et al., 2011), the UK (Parsons et al., 2016; Rosewilliam et al., 2016), and Norway (Berg et al., 2017). These reported studies have explored stroke survivors' and families' desired goals, nature of goals that were set by health care providers, stroke survivors' level of participation and centredness in setting therapeutic goals and the level of satisfaction.

In the field of aphasia, qualitative researchers have adopted qualitative research approaches in their studies. To provide some examples from aphasia literature of studies that reported using specific qualitative approaches, Michallet, Tétreault, and Le Dorze (2003) and Luck and Rose (2007) reported explicitly that they adopted the phenomenological approach in their studies. Hallé, Le Dorze, and Mingant (2014) reported the adoption of the grounded theory approach. Ethnography was used by Tregea and Brown (2013) and Parr (2007) to study topics in aphasia. Case study and narrative approaches have been adopted by Tremblay, Croteau, Le Dorze, and Tremblay (2009) and Mitchell, Skirton, and Monrouxe (2011), respectively. Simmons-Mackie and Lynch (2013) claimed that the majority of studies in aphasia qualitative research literature have not report the adopted approach explicitly; rather, a general term, including "qualitative methods", was used. Based on their literature review, Simmons-Mackie and Lynch (2013) reported that when the approach was reported explicitly, phenomenology and grounded theory were the most commonly used.

1.8.2 Overview of data collection methods

In relation to collecting data in aphasia qualitative research, researcher reported different methods in their studies. To give some examples, Siyambalapitiya, Worrall, and Tomkins (2013), Rose, Worrall, Hickson, and Hoffmann (2011), Dalemans, de Witte, Wade, and van den Heuvel (2009) and Purves (2009) used interviews in their studies to collect data from individuals with aphasia and from their caregivers. To collect data in their studies, Simmons-Mackie et al. (2007) and Ashton et al. (2008) used interviews and observation. Knollman-Porter, Wallace, Hux, Brown, and Long (2015) and Beckley, Best, and Beeke (2017) used questionnaires, in addition to interviews and focus groups, to collect data from people with aphasia and from speech and language therapists (SLTs). Rosewilliam, Sintler, Pandyan, Skelton, and Roskell (2016) used case note data and videos of goal-setting meeting sessions that stroke survivors attended to collect data in their studies.

In the current study, semi-structured in-depth interviews are selected as the method for data collection in addition to PWA's case record data. Choosing semi-structured in-depth interviews was decided because most qualitative studies on aphasia used such method to collect data as discussed in the following sub-section. Moreover, this method was chosen because some researchers advocate the inclusion of PWA in qualitative research by supporting their communication as discussed also in the following section. Supporting the communication of PWA to provide their views is more practical in one-to-one interview, when compared to focus groups for example, because the interaction is focused mainly between the researcher and the person with aphasia. In addition to that, the variation in communication skills among PWA and the differences in their needs for support might be a barrier for some PWA to fully provide their views in focus groups. It could be that PWA might be hesitant to provide their views or feel the pressure to agree with others. Therefore, one-to-one semi-structured in-depth interviews was selected as a method to collect data from PWA in the current study.

Since data in this study is collected using in-depth semi structured interviews, the following sub-section discusses interviewing PWA in qualitative research.

1.8.2.1 Interviewing PWA in qualitative studies

Simmons-Mackie and Lynch (2013) review of studies on aphasia confirmed that interviews are widely used method to collect data in qualitative research. They reported that 75 studies out of 78 used interviews as part of data collection method, and that 60 studies out of these used interviews only as the main source for data. Interviews provide a rich account of participants experiences, views, and feelings on certain topics. By triangulating the source of data including using observations, documented record data, or video records in addition to interviews, research trustworthiness is enhanced. For some researchers, using interviews only to collect data might be the only available option due to restrictions in time and resources, or due to participants’ confidentiality issues.

Interviewing people with communication difficulties is a challenging process for both interviewers and interviewees due to different linguistic and cognitive barriers. These obstacles include the presence of possible memory, learning, language, speech and cognitive difficulties to various degrees (Carlsson, Paterson, Scott-Findlay, Ehnfors, & Ehrenberg, 2007). Luck and Rose (2007) and Carlsson et al. (2007) contended that, to a certain degree, qualitative researchers used to exclude some PWA from interviews and other forms of qualitative methods because of the aforementioned challenges. Carlsson et al. (2007) argued that researchers should aim towards finding strategies with which to facilitate communication when designing interviews for people with difficulties, instead of excluding them. Moreover, the authors stressed the necessity of learning about the nature of the impairment and how it would affect communication generally and interviews specifically. Luck and Rose (2007) argued that valuable data can be collected form PWA when the researcher design data collection methods to meet the communication needs of PWA.

In their review of qualitative research on aphasia, Simmons-Mackie and Lynch (2013) reported that PWA were interviewed in 51 out of 54 studies that included them as participants, and that several studies used strategies to facilitate the communication of PWA while collecting data. The following are examples of studies in which PWA were interviewed: Ashton et al. (2008), Hersh (2009), Matos, Jesus, and Cruice (2014), Rohde, Townley-O’Neill, Trendall, Worrall, and Cornwell (2012) and Worrall et al. (2011). These studies indicate that in recent years, qualitative researchers involved in aphasia have developed awareness of the necessity of including PWA in interviews as important sources, since these individuals live with the actual experience.

Since PWA are the ones living the experience, and since it has been recommended in the literature to include them by facilitating their communication, the following sub-section provides strategies for interviewing PWA, as reported in the literature.

1.8.2.2 Strategies for interviewing PWA in qualitative studies

In the aphasia literature, researcher have followed recommendations reported by Braunack-Mayer and Hersh (2001) and Kagan (1998) so as to assist PWA with understanding all aspects of the study before giving their consent to participate in a research study. To provide some examples of studies that have reported facilitating the communication of PWA when giving their consent to participate, Hersh (2009) Howe, Worrall, Hickson (2008), Rose, Worrall, Hickson, and Hoffmann (2011), and Rose and Luck (2007) stated that they provided aphasia-friendly consent forms with large font, simple language, and pictures. The researchers also reported using pens, papers, and additional drawings and pictures to verify comprehension of PWA.

In relation to interviewing PWA, different studies have suggested and employed various strategies for promoting effective communication with PWA during interviews. These strategies include Talking Mats™ (Bornman & Murphy, 2006; Murphy & Oliver, 2013), communication strategies of communication partners (Simmons-Mackie & Kagan, 1999), supported conversation techniques (Kagan, 1998), general techniques with which to facilitate communication (Luck & Rose, 2007), and the Life Interests and Values (LIV) Cards (Haley, Helm-Estabrooks, Caignon, Womack, & McCulloch, 2009).

Talking Mats™ is an easy-to-use visual system developed at the University of Stirling, which facilitates people with communication difficulties in expressing their thoughts, emotions and needs (Murphy & Oliver, 2013). Talking Mats™ includes three sets of symbols (topics, visual scale, and options) that allow a person to select and think of the choices to place on the mat (Bornman & Murphy, 2006). Different studies have shown that Talking Mats™ supports people with communication difficulties in expressing their thoughts during interviews, and facilitates a person-centred approach during the goal-setting process (Bornman & Murphy, 2006; Murphy & Boa, 2012; Murphy & Oliver, 2013; Murphy, Tester, Hubbard, Downs, & MacDonald, 2005; Lauren K Pettit, Tönsing, & Dada, 2016).

Simmons-Mackie and Kagan's (1999) study aimed to find patterns of good and poor communication strategies used with PWA. They videotaped 10 PWA and 10 individuals without communication impairments during conversations. The videotapes were then evaluated so as to extract the best and worst two conversation partners. Next, the researchers used the conversation analysis method to analyse the interactions of the four pairs. The researchers found some strategies to be facilitative and labelled these as *good*, including acknowledgements (the use of 'yeah', 'right', and head nods), congruent overlap (wherein the partner's response positively overlaps that of the person with aphasia), accommodation (the partner adapts to the communication style of the person with aphasia), and communication repair (the partner uses face-saving strategies). What is more, the researchers reported the following as *poor* strategies: disjunct markers (utterances that indicate disagreement with what was said previously), unsuccessful repair (excessive repetition of the question or suddenly moving to the next one without acknowledging), and unfavourable word choice (helpless). Generally, the researchers described good communication partners as being accepting of genuine responses without stressing correct information, attending to the feelings of the person with aphasia, and being capable of smoothly changing the mode of communication, whereas poor partners were less acknowledging, adaptable and sensitive.

The supported conversation for adults with aphasia (SAC) was developed in the Aphasia Centre in Ontario, Canada (Kagan, 1998). The main aim behind this technique is to minimise the psychosocial effects of aphasia. In this approach the conversation partner learns strategies and then acts as a facilitator for the person with aphasia during conversations in order to enhance the process of exchanging information (Kagan, 1998). These strategies comprise acknowledging (i.e. verbal and non-verbal support, humour, and encouraging tone of voice) and revealing competence. Revealing competence includes three points, namely achieving comprehension (i.e. drawing, gestures and keywords), ensuring that the person with aphasia is capable of responding and expressing thoughts and feelings (i.e. giving him or her time in which to respond, asking yes/no questions, and asking fixed-choice questions), and confirming responses (i.e. expanding, summarising and reflecting) (Kagan, 1998; Kagan, Black, Duchan, Simmons-Mackie, & Square, 2001). In the literature on aphasia, SAC was adopted in order to facilitate conversation while interviewing PWA (Worrall et al., 2011) and was used so as to train nursing staff to communicate effectively with PWA (Jensen et al., 2015).

One of the aims of Luck and Rose’s (2007) qualitative pilot study was to investigate what strategies could be used when interviewing PWA to facilitate their interaction. The authors concluded that valuable information could be elicited from PWA if interviews were adapted to their needs by using certain techniques. Some of the strategies used by the interviewer included acknowledging difficulties during the interaction, using reinforcement, narrowing the question, clarifying (e.g. providing the accurate pronunciation of a mispronounced word), offering words, repeating the interviewee’s response, probing with a yes/no question, giving the interviewee enough time to answer, and paraphrasing the response. Moreover, the authors reported some strategies used by PWA during interviews, including using gestures and facial expressions and asking the interviewer for clarification.

Another tool that can be used to facilitate communication with PWA is the set of LIV Cards (Haley, Helm-Estabrooks, Caignon, Womack, & McCulloch, 2009). Developed in the Department of Communication Disorders and Sciences of Western Carolina University, the LIV tool aims to enhance communication amongst PWA, families and SLTs, as well as decreasing the barriers to goal-setting, assessment, and conversation. The LIV Cards consist of four sets of picture cards (Home & Community, Creative & Relaxing, Physical, and Social), in addition to the manual and scoring sheets. In a study that investigated the application of this tool the researchers found that the set of LIV Cards were a successful facilitative aid for PWA in identifying their current and preferred activities (Haley, Womack, Helm-Estabrooks, Lovette, & Goff, 2013).

Studies in the literature that used interviews to collect data from PWA reported using the above reported communication support methods. Most studies reported using Kagan's (1998) strategies and the Talking Mats™ approach to support PWA’s comprehension and expression during interviews. To give examples of some studies, Matos, Jesus, and Cruice (2014), Lawton, Haddock, Conroy, Serrant, and Sage (2018), Siyambalapitiya et al. (2013), Gillespie, Murphy, and Place (2010), Howe,Worrall, and Hickson (2008), Hersh (2009), Dalemans et al. (2009), and Pettit et al. (2016) reported using Kagan's (1998) strategies and the Talking Mats™ in their studies they conducted with PWA.

1.8.3 Overview of data analysis methods

The literature on stroke and aphasia shows that researchers have utilised different methods in analysing qualitative data. Researchers selected analysis methods based on the aims of the studies, researchers' own perspectives, and the type of data collected. Stroke and aphasia qualitative studies reported adopting content analysis, grounded theory, and thematic analysis.

Different researchers in the literature on aphasia and therapeutic goals have adopted content analysis as the main method with which to analyse qualitative data in their studies. Content analysis was used to study third-party disability (Grawburg, Howe, Worrall, & Scarinci, 2019). When the main aim was to identify, compare or analyse goals of PWA, families and SLTs, researchers including Hersh et al. (2012a), Howe et al. (2012), Rohde, Townley-O'Neill, Trendall, Worrall, and Cornwell (2012), Sherratt et al. (2011) and Worrall et al. (2011) adopted the method of content analysis. Most researchers in the field of aphasia mapped the categories emerged from content analysis to The International Classification of Functioning, Disability and Health (ICF) (World Health Organisation, 2001).

The ICF (World Health Organisation, 2001) is a framework that provides a universal definition of health conditions and consequences according to three main components: Body Structure and Function, Activities and Participation, and Personal and Environmental Factors. Within each ICF component, there are chapters and detailed classifications. For example, the ICF component Activities and Participation includes Chapter 1, i.e. Learning and applying knowledge; within this chapter, there are detailed classifications including d130 Copying, d135 Rehearsing, and d140 Learning to read. Using this framework to describe a health condition is a hierarchical procedure that includes one of the following levels:

1- One-level classification: Chapters level.

2- Two-level classification: Chapters and first classification level.

3- Detailed classification with definitions: Chapters and all classification with definitions, inclusions and exclusions.

In stroke and aphasia literature, different studies used the ICF framework to analyse needs, goals, consequences and desired outcomes (Matos, Jesus, & Cruice, 2014; Sumathipala, Radcliffe, Sadler, Wolfe, & McKevitt, 2012; Wallace et al., 2016; Worrall et al., 2011). This method allowed researchers to understand which areas in the lives of patients or families were affected most by the health condition, in addition to the distribution of needs, outcomes and goals across the ICF component. Moreover, the method allowed researchers to compare the views of participants in an organised framework.

Simmons-Mackie (2004) and Threats and Worrall (2004) argued that this broad system of the ICF framework could be considered as a disadvantage. The broad codes might not be sensitive to identify aspects of communication difficulties or capture subtle changes (Simmons-Mackie, 2004; Threats & Worrall, 2004). Davidson, Worrall, and Hickson (2003) also reported that communication disorders and daily interactions are complex and that many factors present in a context might not be captured while using the ICF framework. In the literature of ICF and communication disorders, researchers have also discussed another limitation of the ICF framework. It has been argued that the individual’s own perspective on the experience is not captured by the ICF framework, hence losing an important viewpoint (Duchan, 2004; Simmons-Mackie, 2004).

It has been suggested in the literature that more research is needed to inform the ICF framework so that it becomes more reflective and capture more aspects in the field of speech and language disorders (Worrall & Hickson, 2008; Worrall, McCooey, Davidson, Larkins, & Hickson, 2002). Threats (2006) argued that the ICF framework allows clinicians working with people with aphasia to understand patients' needs, rather than assessing or treating them without this knowledge.

Researchers in the field of stroke and aphasia have used the grounded theory approach to data analysis when the main aim of their research has been to investigate an understudied phenomenon and develop a new theoretical understanding of it. Studies conducted by Hersh (2009), Hallé, Le Dorze, and Mingant (2014), Lawler et al. (1999) and Hallé and Le Dorze (2014) reported the use of grounded theory in investigating the views and experiences of PWA, significant others, and SLTs in relation to different aspects of aphasia therapy including discharge (Hersh, 2009), rehabilitation (Hallé & Le Dorze, 2014; Hallé, Le Dorze, & Mingant, 2014), and the role of goal-setting in late stroke recovery (Lawler et al., 1999).

In relation to thematic analysis, researchers have reported using this method to inductively analyse interview data in order to understand participants' perceptions of the stroke experience (Kitson et al., 2013; Nasr et al., 2016; Parr, 2007; Thomas, Allison, & Latour, 2018), goal-setting participation (Morris, Clayman, Peters, Leppin, & Leblanc, 2015), and therapeutic alliance (Lawton, Haddock, Conroy, Serrant, & Sage, 2018).

The selected analysis methods used in this study are reported in details with justifications in chapter 3 (Selection of analysis and translation methods) under *3.2 Selected analysis methods: Reflections and justifications.*

1.8.4 Strength and limitations of qualitative methodologies

Damico, Simmons-Mackie, Oelschlaeger, Elman, and Armstrong (1999) reported both strengths and limitations of qualitative methodologies when utilised in aphasia research. Regarding the strengths, they stated that qualitative research would lead to a rich understanding, as it would allow the researcher to study aphasia in its natural setting. Additionally, the researcher would act as a data collection instrument, and the data collection and analysis methods would be flexible and adjustable with respect to the needs of the study. Furthermore, qualitative research would enable the researcher to collect descriptive and detailed data so as to understand the target phenomenon thoroughly. Finally, this kind of research would allow understanding the views of people living the experience and its ways of occurring, rather than measuring outcome behaviour (Damico, Simmons-Mackie, Oelschlaeger, Elman, & Armstrong, 1999). Regarding the limitations, Damico, Simmons-Mackie, Oelschlaeger, Elman, and Armstrong (1999) stated that qualitative projects would require the researcher to put more effort into data collection and analysis than would quantitative research. They, stated that only a small number of researchers are experienced in qualitative research and that new researchers in this field would need to develop certain skills and undergo training in qualitative strategies. Other drawbacks of qualitative research include the challenging process of evaluating research rigour and the generalisability of findings. Finally, the authors pointed out that this type of research has always been criticised for its methodological rigour as standardised measures are not used which could increase subjectivity in findings (Damico et al., 1999). Bowling (2014) argued that the results of qualitative research are usually used to understand a topic deeply, rather than the results being generalised to the general population since the number of participants in qualitative research is relatively small.

The qualitative research limitations could be avoided by applying different strategies in the use of research methods. Computer Assisted Qualitative Data Analysis (CAQDAS) software can be utilised in order to save time and manage data more efficiently (e.g. NVivo and ATLAS.ti). Furthermore, the researcher could pilot the interview questions before conducting the main study in order to modify some elements, build confidence and master interviewing skills. As for research rigour, techniques reported in the literature could be adopted so as to ensure research trustworthiness; for example, reliability checks, rich presentation of participants' responses, and detailed presentation of analysis steps (e.g. Gibbs, 2007; Lincoln & Guba, 1985; Morse, Barrett, Mayan, Olson, & Spiers, 2002; Noble & Smith, 2015; Shenton, 2004). Regarding generalisability, a detailed presentation of research context can facilitate transferability of results to other contexts. Moreover, Denscombe (1998) and Stake (1994) argued that individual cases included in qualitative research are part of the population; thus, complete rejection of generalisability should not be applied.

Overall, the cited literature shows that qualitative research can serve the field of aphasia and contribute to the discipline because of the qualities and strengths of this methodology. When conducted appropriately by considering research rigour, qualitative research becomes a powerful tool with which to investigate target areas thoroughly.

1.8.5 Aphasia and qualitative research in the Saudi context

There is a lack of studies carried out in Arabic, specifically in Saudi Arabia, which have investigated aphasia from a social model approach and with using qualitative methods. The literature shows that Al-Haidary, Qannam, and Lam (2015) and Al Jadaan (2015) investigated two aspects in Saudi Arabia: neurological rehabilitation goals and the quality of life (QoL) of PWA. Al-Haidary, Qannam, and Lam (2015) conducted a study that aimed to develop a rehabilitation goal menu for inpatients in a neurological rehabilitation facility in Saudi Arabia. In their study, 130 patients were recruited from a rehabilitation hospital to conduct semi-structured interviews and focus groups. The researchers conducted a cross-sectional study to measure patients' goal rankings. By the end of their study, Al-Haidary, Qannam, and Lam (2015) were able to create a goal menu containing 10 items. The researchers concluded that the highest-ranked rehabilitation goal was functional mobility, followed by self-care and religious goals. With regard to the quality of life of PWA, Al Jadaan (2015) conducted a study that aimed to find out factors affecting the QoL of Saudi PWA by collecting and analysing information from interviews with PWA and from an online survey to SLTs in Saudi Arabia. Based on the findings, the researcher systematically developed an assessment questionnaire that aimed to rate areas within the following domains: physical and daily life activities, communication, interests and leisure, religious activities, social relationships, and feelings and emotions. By developing such tools, Al-Haidary, Qannam, and Lam (2015) and Al Jadaan (2015) contributed to clinical practice in Saudi Arabia. This indicates that there is a move towards a better understanding of Saudi PWA's needs and life outside of the clinic. Clinical services, therapeutic goals, and delivery approaches have not however been fully explored for PWA in Saudi Arabia.

There is therefore a move toward adopting qualitative methods to explore experiences from PWA's perspectives and investigate aphasia's impact on people's lives. This type of research is limited however in the Saudi context which indicates that the views of the Saudi population with aphasia need to be further explored. As the topic for this thesis is to explore therapeutic goal-setting within the context of individuals' experience of stroke and aphasia, qualitative methods have been selected. Qualitative research methodology allows gathering rich and in-depth views on a certain phenomenon from individuals who are going through the experience, thus allowing a researcher to explore an issue in depth. When no previous research is conducted and little is known about a phenomenon, qualitative methods is considered appropriate to explore topics.

Since the previous sections covered aphasia and qualitative research, the following section presents an overview of the literature on the experience of stroke and aphasia before discussing goal-setting in aphasia rehabilitation.

1.9 The experience of stroke and aphasia

Within this section, two sub-sections are presented below in which to present studies that explored the experience of stroke, and studies that focused on the experience of post-stroke aphasia.

1.9.1 Qualitative studies of stroke experience

Understanding how PWA and their families experience the medical condition contributes to the knowledge possessed by researchers and healthcare professionals and taking part in such studies potentially aids the participants themselves. This knowledge facilitates widening the perspectives of healthcare professionals to consider broad, contextual, influential factors that could influence therapy, as well as to embrace a PWA and family-centred approach to rehabilitation.

There has been substantial research exploring how stroke survivors and their families have constructed their experience of undergoing stroke. Some studies have reported a shared account of stroke survivors' and families' experience, while others focused on the accounts of separate groups. These studies aimed to draw general themes in order to find common patterns in respect of participants' experience. Participants in the majority of these studies are drawn from the larger population of stroke survivors as opposed to the narrow group of PWA with little explicit reference to the representation of PWA in the studies. For examples, Simeone, Savini, Cohen, Alvaro, and Vellone (2015) stated that PWA were not included in their study. Luker et al. (2017), Martin-Saez and James (2019), and Lawrence (2010) conducted systematic reviews to explore the experience of stroke and found that 3 out of 34, 3 out of 10, and 3 out of 4 studies included PWA, respectively. Several studies that explored the experience of stroke survivors did not provide further information regarding the presence of aphasia amongst participants (Kitson et al., 2013; Nasr et al., 2016).

Most studies have explored the experience of stroke survivors and their informal carers. Kitson, Dow, Calabrese, Locock, and Athlin (2013) explored acute stroke experience in the hospital, while Nasr, Mawson, Wright, Parker, and Mountain (2016), Lou, Carstensen, Jørgensen, and Nielsen (2017), Simeone, Savini, Cohen, Alvaro, and Vellone (2015) explored living life after the occurrence of stroke. Lawrence (2010) explored specifically in their systematic review the young adults' experience of stroke, and Martin-Saez and James (2019) investigated how occupational identity is changed following the occurrence of stroke. Anderson et al., (2017), Bäckström et al., (2010), and López-Espuela et al., (2018) focused in their studies on marital relationships following the occurrence of stroke when communication between partners can be compromised. Substantial research into the impact of stroke on families has been conducted. Two systematic reviews synthesised some of the research in this area and explore caring and adaptation (Greenwood & Mackenzie, 2010; Hesamzadeh et al., 2015).

The findings of these studies show that the condition negatively impacted individuals who underwent the experience. The lives of stroke survivors and their families have to be rebuilt around stroke (Lou et al., 2017; Nasr et al., 2016), and the perception of oneself is redefined in relation to the illness (Lawrence, 2010; Martin-Saez & James, 2019; Nasr et al., 2016). Changes in roles and relationships occur and a loss of previous life is experienced following the sudden occurrence of stroke (Anderson et al., 2017; Bäckström et al., 2010; Greenwood & Mackenzie, 2010; López-Espuela et al., 2018; Lou et al., 2017; Nasr et al., 2016; Simeone et al., 2015). Stroke survivors experience feelings of distress, being overwhelmed, and being a burden on carers (Kitson et al., 2013; Simeone et al., 2015), and family members who play the roles of carers experience grief, distress and uncertainty (Greenwood & Mackenzie, 2010; Hesamzadeh et al., 2015). Adaptation to all of these changes is a dynamic process and context-based. Adaptation is facilitated by personal determination and wider social support (Hesamzadeh et al., 2015).

1.9.2 Qualitative studies of aphasia experience

The literature on stroke and aphasia shows that studies which reported the inclusion of PWA have been conducted to understand the rehabilitation experience, family and social relationships, third-party disability, and living successfully with aphasia. The following sub-sections present examples from the literature.

1.9.2.1 The rehabilitation experiences

Ferguson et al. (2010) conducted a study to explore the experience of PWA and their families in rehabilitation, and Luker et al. (2017) conducted a systematic review to explore carers' experience during inpatient stroke rehabilitation and reported that three of the studies included focused on the experience of aphasia.

Ferguson et al. (2010) aimed to describe the experience of PWA, their families, and SLTs in aphasia rehabilitation in Australia through metaphor. The researchers studied and analysed the interviews of five PWA, five of their family members, and eight SLTs through the use of descriptive linguistic methods in order to extract metaphorical concepts. Across the three participant groups, the researchers found that the most frequent present concepts were as follows: Journey (e.g. "tracks"), Battle (e.g. "fighting"), and Product (e.g. "we'd just been processed”). The researchers concluded by highlighting the social disempowerment that could be reflected by the metaphorical concepts of Battle and Product.

Luker et al. (2017) included 33 qualitative studies with a total number of 452 carers as participants. The included studies were published between 1998 and 2015 and conducted in the UK, the USA, Canada, Sweden, Australia, Singapore, Ireland, Germany, and New Zealand. Amongst the 33 studies included in the systematic review of Luker et al. (2017), three studies focused on the experience of aphasia from the perspectives of families. These studies explored families’ own goals in the rehabilitation process (Howe et al., 2012), information needed (Avent et al., 2005), and significant others’ general experience of aphasia rehabilitation (Hallé & Le Dorze, 2014). Luker et al. (2017) stated that distress and feeling overwhelmed were present in carers because of the experience as well as the new environment of rehabilitation in which they were present. A more inclusive rehabilitation environment was a recall to decrease distress, as carers desired to be heard, informed and included as part of the collaborative team.

1.9.2.2 Family and social relationships

The reciprocal relationships between stroke survivors with aphasia and other members of the family could be affected, thus changing the dynamics of families. Studies were conducted so as to understand the impact of aphasia upon the parent–child relationship (Hallé et al., 2011; Le Dorze et al., 2009). Meanwhile, other studies focused on marital relationships following the occurrence of stroke and aphasia, when communication between partners can be compromised (Anderson et al., 2017).

Le Dorze, Tremblay, and Croteau (2009) studied the father–daughter relationship following post-stroke aphasia, whereas Hallé, Duhamel, and Le Dorze (2011) studied the mother–daughter relationship, also following post-stroke aphasia. Both studies concluded that the relationship dynamics change after stroke and aphasia, and that communication changes are a major element in altering the dynamics. Aphasia can impact on marital relationships (e.g. Williams & Freer, 1986). Communication after the occurrence of stroke was an area of challenge, and that the marital relationship can be jeopardised, since it is often reframed around stroke as a medical condition (Anderson et al., 2017).

Some studies have focused on the impact of aphasia upon relationships in relation to the wider social circle. Fotiadou, Northcott, Chatzidaki, and Hilari (2014) analysed blog data of PWA following stroke and found that there was reduced contact with friends and the wider social network, as well as changes in family relationships, all of which were due to the increased dependence and the changed physical and communication abilities. Parr's (2007) findings demonstrated that social exclusion is a common experience amongst people with severe aphasia. Social exclusion could be observed at different levels, including infrastructural (e.g. employment and services), interpersonal (e.g. family and society) and personal (e.g. identity) levels (Susie Parr, 2007). These many and deep levels of social exclusion have been confirmed in different studies, including Davidson, Howe, Worrall, Hickson, and Togher (2008), Northcott, Moss, Harrison, and Hilari (2016), Parr (2001), and Pike, Kritzinger, and Pillay (2017). What is more, the impact of such social exclusion upon individuals’ well-being and mental health has been revealed. Northcott, Moss, Harrison, and Hilari (2016) found that depression is associated with reduced social participation and a lack of social support after the occurrence of stroke. Moreover, depression has been identified as being one of the quality of life predictors following stroke, alongside a functional status (Carod-Artal, Egido, González, & Seijas, 2000).

1.9.2.3 Third-party disability

In an attempt to explore the impact on caregivers, the International Classification of Functioning, Disability and Health (ICF) framework of the World Health Organization (WHO) has been used to frame the experiences reported (World Health Organization, 2001). The WHO defines the overall negative impact on family members who take care of a person with a medical condition as a "third-party disability". The ICF framework provides a standardised language for describing medical conditions according to three main components, namely: Body Structure and Function, Activities and Participation, and Personal and Environmental Factors. Research investigating third-party disability in family members of PWA has found that the negative impact on carers' lives spans a wide range of domains within the components of Body Structure and Function and Activities and Participation (e.g. Grawburg, Howe, Worrall, & Scarinci, 2013a, 2013b, 2014, 2019; Threats, 2010). Therefrom, researchers have argued for a family-centred rehabilitation to address family members' concerns (e.g. Grawburg, Howe, Worrall, & Scarinci, 2013a, 2013b, 2014, 2019).

Although several studies have found that carers report a range of negative experiences and impacts on their lives when living with a stroke survivor with aphasia, there are also reports of positive effects of the condition of aphasia upon their lives. There are reports that positive outcomes for family members include personal growth, improvement of relationships with family members, appreciation of life and finding meaning, hopefulness and pride in achievements, and networking with new people (Grawburg, Howe, Worrall, & Scarinci, 2012; Grawburg et al., 2013a; Winkler, Bedford, Northcott, & Hilari, 2014).

1.9.2.4 Living successfully with aphasia

Living successfully with aphasia has been investigated from the perspectives of PWA, their families, and SLTs. Studying the impact of stroke and aphasia upon stroke survivors and their families has allowed researchers to detect critical factors that could either facilitate or hinder adaptation to the new situation. As reported by Worrall et al. (2010), developing the ability to live successfully with aphasia is an individual process that differs from one person to another, and requires time after the occurrence of stroke.

The degree of family and social support has been a common theme in many of these studies (Fotiadou et al., 2014; Kokorelias et al., 2019; Northcott et al., 2016; Winkler et al., 2014). Family members and spouses of PWA reported that emotional support and practical support constituted some of their needs as carers (Le Dorze & Signori, 2010; Michallet, Le Dorze, & Tétreault, 2001; Michallet, Tétreault, & Le Dorze, 2003). Amongst PWA, their families, and SLTs, living successfully with aphasia was closely linked to being part of meaningful relationships and positive interactions (Boles, 2006; Brown, Worrall, Davidson, & Howe, 2011a, 2011b; Cruice, Worrall, & Hickson, 2006) that are full of acceptance and support (Brown et al., 2011a).

Moreover, living successfully with aphasia has been found to be related to being involved in life and participating in meaningful activities (Brown et al., 2011b; Cruice et al., 2006). Holland and Nelson (2018) suggested participating in positive disciplined behaviours (e.g. attending therapy or volunteering) and being committed to full living (e.g. strengthening family relationships or learning a new skill) for PWA and their families aiming towards living well with the condition.

Research into the experience of stroke revealed that the lives of stroke survivors and their informal carers are heavily impacted by stroke and rebuilt around it. Research that focused specifically on aphasia post stroke explored the experience of rehabilitation, family and social relationships, third-party disability, in addition to living successfully with aphasia. The literature review shows that these studies are conducted heavily in Western or English-speaking countries with lack of research conducted in Arab countries and specifically Saudi Arabia. Moreover, the literature review shows that the cultural context of people's experience is less reported in these studies.

Since the aim of this study is to explore goal-setting within the context of stroke and aphasia experience in Saudi Arabia, the next section presents an overview of therapeutic goal-setting in neurological rehabilitation and aphasia literature.

1.10 Goal-setting in the context of the study

The following two sub-sections presents therapeutic goal-setting within the context of the current study. At first, goal-setting in medical rehabilitation is discussed. Then, goal-setting in post-stroke aphasia rehabilitation is reported.

1.10.1 Goal-setting in medical rehabilitation

Within this sub-section, definitions of goals and the process of goal-setting in medical rehabilitation are reported. Then, an overview of studies in neurological rehabilitation is presented, and therapy outcome is discussed in relation to goal-setting.

1.10.1.1 Therapeutic goals in medical rehabilitation

A goal is defined in psychology as the end or future state that an individual desires or aims to reach (Brunstein, Dangelmayer, & Schultheiss, 1996; Brunstein, Schultheiss, & Maier, 1999; Moskowitz, 2012).

In the context of medical rehabilitation, Tolman (1932) and Wade (2009) reported that goals do not represent only end states; rather, they include also the means that lead the individual to achieve a certain goal. This indicates that a goal could be divided into subgroups that include sub-goals (or objectives), which lead to the main goal. Related to this, Kruglanski et al. (2002) proposed a cognitive theory of a goal system, claiming that goals, sub-goals, and means by which to attain them are all dynamically connected in a complex way. Wade (2009) stated that medical rehabilitation goals have two features. The first feature is that a goal is a future state. This means that current behaviours are changed to be different in future, or preserved, as in severe cases. The second feature is that a goal in medical rehabilitation reflects also the actions taken by the rehabilitation team so as to achieve a future state.

Goals are described in the literature as being hierarchical (Bradley, Bogardus Jr, Tinetti, & Inouye, 1999; Wade, 2009). Thus, in a hierarchy, goals descend from broad to narrow, and are categorised into general and specific. General goals could be set in relation to values, whereas specific goals aim to control actions (Bradley et al., 1999). Wade (2009) reported that different aspects could govern the hierarchy of goals, including time (e.g. long-term goals) and concepts (e.g. Maslow’s hierarchy of needs that includes physiological, safety, love/belonging, esteem and self-actualization).

In medical rehabilitation a goal could also be SMART. Playford, Siegert, Levack, and Freeman (2009) claimed that Schut and Stam (1994) were the first to introduce the SMART goal approach in medical rehabilitation. As Schut and Stam (1994) reported, the acronym SMART stands for specified, motivating, attainable, rational and timed. In the literature a variation was found in words that represent the acronym SMART (Wade, 2009); however, it is generally accepted that SMART represents the following: specific, measurable, achievable, realistic and time-bound (Hersh, Worrall, Howe, Sherratt, & Davidson, 2012b).

1.10.1.2 The process of goal-setting in medical rehabilitation

The process of choosing the goal that the individual desires to achieve is another concept discussed in the literature. Gollwitzer (1993) reported that goal-setting is the process of evaluating the options of goals to select from by considering aspects including desirability, value and attainability. Goal-setting in medical rehabilitation refers to the process of formal planning and negotiation of goals between rehabilitation professionals, individuals' with the condition and/or their family members, in addition to the explicit justification of practised activities (Wade, 2009). Theories, formal goal-setting tools, and recommendations for practices have been proposed in the literature. However, there is no evidence on agreements upon the best approach in clinical practice (Playford et al., 2000), which could indicate that goal-setting in rehabilitation is a complex process and context-based.

Bradley et al. (1999) proposed a theory of goal-setting for chronic diseases in clinical medicine. They reported that a patient's values and beliefs could be used as a guide from which to generate general goals. From the general goals, smaller and more specific goals are established in order to plan the intervention. They argued in their paper that goal-setting is complex and influenced by different modifying factors including the patient's characteristics, medical condition, and the nature of interactions between patients, families and clinicians. They concluded that goal-setting in clinical medicine is a challenging process, and that there are chances of disagreements between clinicians and patients regarding goals; thus, clear discussions and interactions are emphasised.

Scobbie, Dixon, and Wyke (2011) proposed a practice framework of goal-setting and action planning (G-AP) in medical rehabilitation. The G-AP framework consists of four elements: goal negotiation, goal identification, planning, and appraisal and feedback. In a study that aimed to evaluate the implementation of the G-AP framework the researchers concluded that participants with stroke and healthcare professionals in the rehabilitation setting viewed the tool as being useful; however, more examination is required (Scobbie, McLean, Dixon, Duncan, & Wyke, 2013). The researchers also reported that they had improved the framework as they combined goal negotiation and setting in one phase (Scobbie, McLean, Dixon, Duncan, & Wyke, 2013).

General strategies underlying the goal-setting processes have been presented in research studies, including the recommendations suggested by Schut and Stam (1994) and Wade (2009). However, Playford et al. (2000) contended that the research literature lacks evidence of the best approach to goal-setting in rehabilitation. Some of the goal-setting requirements that Schut and Stam (1994) reported include setting motivating goals, defining goals in behavioural terms and explicitly identifying goals to be achieved. Some of Wade’s (2009) suggestions regarding goal-setting strategies include considering the wishes and expectations of patients and families, discussing realistic and non-realistic expectations, discussing means by which to achieve goals, discussing expected outcomes, and the documentation of goals so as to evaluate progress. Both Schut and Stam (1994) and Wade (2009) reported some advantages of undertaking a formal goal-setting process in medical rehabilitation. They claimed that such a process motivates the patient, ensures that the patient and team are working towards the same goal, promotes teamwork and decision making, and monitors and evaluates the rehabilitation process.

1.10.1.3 Overview of studies in neurological rehabilitation

In some of the neurological rehabilitation studies (including stroke rehabilitation) that explored goal-setting, qualitative methods have been used to collect participants' perspectives (e.g. Berg et al., 2017; Brown et al., 2014; Holliday, Ballinger, & Playford, 2007; Parsons et al., 2016; Van De Weyer, Ballinger, & Playford, 2010), as well as to investigate the interaction in goal-setting (e.g. Barnard, Cruice, & Playford, 2010; Levack, Dean, Mcpherson, & Siegert, 2006).

Studies through which to understand multiple perspectives on goal-setting in rehabilitation have been conducted. Triadic or dyadic views on a certain topic can be collected in order to enhance understanding of a phenomenon, compare views, and investigate common influential factors. In this context, studying views of triads means exploring the views of three participant groups, whereas studying dyadic views means exploring the views of two groups. The research literature on goal-setting in the area of neurological and aphasia rehabilitation reveals studies which have explored multiple views on the same issue using triads (e.g. Conneeley, 2004; Lawler et al., 1999; Levack, Dean, Siegert, & McPherson, 2011; Young, Manmathan, & Ward, 2008). Collecting triadic views has not been adopted by many researchers in the field of aphasia when studying goal-setting, which suggests that triadic views are not heavily researched. This could be attributed to factors including the time-consuming data management and analysis processes, in addition to the complexity of analysis triadic data. In the literature of aphasia and qualitative research in Saudi Arabia, there is no evidence of studies that have adopted this method to explore a topic and study views of participants.

Research into goal-setting in neurological rehabilitation, including stroke rehabilitation focused on exploring goal-setting by studying certain topics. Four systematic reviews that aimed to address different issues including barriers and facilitators, client-centredness, and describing the approaches have been reported.

Plant, Tyson, Kirk, and Parsons (2016) investigated, in particular, barriers and facilitators in relation to goal-setting in stroke rehabilitation. They concluded that individuals' tailored goal-setting approaches, using techniques to facilitate understanding and to avoid unrealistic expectations, are the main facilitators of goal-setting. Plant, Tyson, Kirk, and Parsons (2016) also reported that knowledge, skills, experience and the level of engagement are factors that could be either facilitators or barriers if they were present or not.

Rose, Rosewilliam, and Soundy (2017) conducted a systematic review into shared clinical decision making in rehabilitation settings, reporting that only two studies reported a patient-centred approach to goal-setting, while goal-setting in the other 13 studies was therapist-led. Furthermore, they found that some individuals were motivated to participate in goal-setting, while others wanted decisions to be made by clinicians. Individuals receiving rehabilitation services who participated in decision making reported some advantages including increasing confidence and motivation with respect to reaching goals that were set for rehabilitation.

In a systematic scoping review that was conducted mainly to investigate goal-setting approaches reported in the literature in the context of acquired brain injury rehabilitation, Prescott, Fleming, & Doig (2015) reported that client-centredness and collaboration are major components of effective goal-setting They included 62 studies that described goal-setting approaches, and 24 studies that evaluated goal-setting approaches. The researchers found that the majority of studies reported formal goal-setting approaches (77%) including Goal

Attainment Scaling (GAS), the Goal Setting and Action Planning Framework, and the Canadian Occupational Performance Measure (COPM), whereas 23% reported informal goal-setting approaches including client-centred/collaborative goal-setting or therapist-driven goal-setting.

Sugavanam, Mead, Bulley, Donaghy, and van Wijck (2013) concluded from their systematic review that studies on goal-setting are heterogeneous and that a conclusion is difficult to draw. The researchers reported also that the extent of patients' participation was not clear in the studies included in their systematic review, and that more barriers to goal-setting were identified in comparison to facilitators. Sugavanam, Mead, Bulley, Donaghy, and van Wijck (2013) indicated that the process of goal-setting in stroke rehabilitation can help positively in stroke survivors' engagement, progress, performance and in reaching goals.

1.10.1.4 Goal-setting and therapy outcome in neurological rehabilitation

Inconsistencies have been reported in the literature with regard to the relationship between goal-setting and acquired brain injury rehabilitation outcomes. Some studies have reported positive effects of goal-setting, but a conclusion on what level of participation in goal-setting or what goal-setting approach is directly correlated with a positive rehabilitation outcome remains unclear (Levack et al., 2016; Levack et al., 2006). The challenge in drawing such a conclusion from the literature on the effect of goal-setting on outcomes is related to different issues including the complexity of medical conditions reported in studies, different outcome measures used in studies and reported in the literature, the nature of outcome measures used and the fact that they might not be able to detect changes at different levels in the brain, problems in study designs, and different methods of studies reported in the literature (Levack et al., 2006; Levack et al., 2016; Prescott et al., 2015).

With regard to the positive effect of goal-setting in rehabilitation, two studies have reported that patients' involvement increases the number of goals set without compromising achievement, in addition to attaining a higher quality of life, sense of well-being, and self-efficacy (Dalton et al., 2012; Levack et al., 2006). Furthermore, studies concluded that increased participation in goal-setting is related increased motivation for therapy (Leach, Cornwell, Fleming, & Haines, 2010), higher satisfaction, and better goal achievement, all of which lead to better functional outcomes (Turner-Stokes, Rose, Ashford, & Singer, 2015).

1.10.2 Goal-setting in post-stroke aphasia rehabilitation

Within this sub-section, therapeutic goals in aphasia rehabilitation are discussed. Then, clinical recommendations related to goal-setting are reported from stroke and aphasia guidelines available in the literature.

1.10.2.1 Therapeutic goals in aphasia rehabilitation

In aphasia rehabilitation, therapeutic goals can be described and categorised based on their features. Hersh et al. (2012a) conducted a qualitative study to investigate the nature of goals in aphasia therapy, interviewing 34 speech and language therapists in Australia. They concluded that aphasia therapeutic goals could be categorised into the following concepts: desires, SMART, impairment and functional, steps, contracts, and implicit goals.

Goals were defined in Hersh et al.'s (2012a) study as the desires of patients. When asked about desired goals the literature revealed that stroke and aphasia patients reported a variety of goals including regaining physical function, improving communication, returning to previously performed activities, receiving education and contributing back to society (Laver et al., 2010; Rohde et al., 2012; Worrall et al., 2011). Furthermore, the literature revealed that a mismatch of goals could be found between SLTs and PWA (Rohde et al., 2012). This mismatch of goals could be attributed to the severity of the patient's case, the service delivery approach, and SLTs' scope of practice (Rohde et al., 2012). The literature on goals in aphasia rehabilitation revealed that family members of patients with stroke and aphasia have desired goals for themselves and for their relatives with medical conditions. They expressed that they wanted to be included in rehabilitation, receive education regarding the medical condition, receive training and be supported and given hope (Howe et al., 2012). However, family members are not always included in the rehabilitation process. In the literature, SLTs attributed the lack of family members' goals to time constraints and families' decision not to be engaged (Sherratt et al., 2011). For their close relatives with medical conditions, family members reported that they desired overall improvement, as well as noticing improvement in their communication skills (Howe et al., 2012; Lawler, Dowswell, Hearn, Forster, & Young, 1999).

In relation to impairment and functional aphasia goals, SLTs in different studies have reported setting impairment-based goals for PWA (Laliberté, Alary Gauvreau, & Le Dorze, 2016; Leach et al., 2010; Rohde, Townley-O'Neill, Trendall, Worrall, & Cornwell, 2012). Aiming to reach a balance between setting impairment- and functional-based goals has also been reported by Sherratt et al. (2011) and Leach et al. (2010) in their studies. Worrall et al., (2011) reported that majority of PWA's goals in their study were linked to the activity and participation domain of the ICF framework (World Health Organisation, 2001). Although the majority of goals expressed by PWA in that study were life goals, it has been argued that these goals should not be alternatives to specific language goals. Duchan and Black (2001) argued that functional and impairment-based approaches enhance each other based on the complexity of the individual's case. They emphasised the notion of designing an approach that will enhance the overall life of PWA (Duchan & Black, 2001).

In the aforementioned study by Hersh et al. (2012a), aphasia therapeutic goals were also viewed as being SMART. In another study by Hersh et al. (2012b) the researchers proposed a framework of SMARTER goals in aphasia rehabilitation that aim to promote a collaborative goal-setting process. In their study, SMARTER refers to Shared, Monitored, Accessible, Relevant, Transparent, Evolving and Relationship-centred (Hersh et al. 2012b). In Hersh et al. (2012a), goals were also viewed as steps, with long-term goals being broken down into sub-goals so that they could be managed more efficiently. Hersh et al. (2012a) suggested that clients' desired long-term goals could be monitored by establishing sub-goals in which they become part of the contract. Such a contract promotes a more collaborative approach to goal-setting and allows SLTs and PWA to evaluate the intervention. Hersh et al. (2012a) reported that implicit goals in their study referred to goals that SLTs practised but that were not necessarily documented or discussed with PWA and their families. SLTs in Hersh et al. (2012a) justified that by mentioning that they considered some of these goals to be important, but the patient did not. Furthermore, SLTs reported that some goals were difficult to measure or included modification of a family member's behaviour.

1.10.2.2 Goal-setting recommendations in stroke and aphasia guidelines

According to the National Clinical Guideline for Stroke provided by the Royal College of Physicians in the UK, goal-setting is a central component in stroke rehabilitation (Rudd, Bowen, Young, & James, 2017). As defined in the National Clinical Guideline for Stroke, goal-setting is the activity in which an individual with stroke, their family (if they are willing) and the rehabilitation specialists identify meaningful, challenging, valued and time-bound goals. Stroke and aphasia guidelines have emphasised cultural sensitivity and the involvement of PWA and their family members in the process.

The Canadian, New Zealand, and Australian stroke recommendations stress on understanding and respecting cultural values of stroke survivors in rehabilitation (Hebert et al., 2016; Stroke Foundation, 2010, 2017). A review of best practice recommendations for aphasia resulted in resulted in 10 best practice recommendations (Simmons-Mackie et al., 2016). It has been stated in the recommendations that PWA and their families should be given information on the options in respect of treatment, and that services should be sensitive to a person's culture and that families need to be included that the intervention should be designed to enhance their life and communication skills (Simmons-Mackie et al., 2016). In spite of this emphasis on cultural sensitivity, there is a lack of research that explores goal-setting from a wider perspective that includes stroke survivors' culture and the context of their experience.

The UK National Clinical Guideline for Stroke proposed general recommendations related to goal-setting in stroke rehabilitation, including understanding the wishes and goals of patients, helping stroke survivors to understand the process of goal-setting, involving them when identifying goals, and supporting them in self-managing their goals (Rudd et al., 2017). In a report on Australian best practice in aphasia rehabilitation it was stated that goals should be a reflection of a person's and family's needs and that goal-setting should be discussed in a collaborative context (Power et al., 2015). In a systematic review of the current post-stroke aphasia guidelines the importance of including PWA and caregivers in the identification of goals was also highlighted (Shrubsole, Worrall, Power, & O'Connor, 2016). In spite of the current emphasis on practical guidelines and research which recommends including stroke survivors and their families in the goal-setting process, some studies have indicated that best practice may not always be adhered to. Studies have reported that goal-setting has often been clinician-led, and that there is a limited inclusion of stroke survivors and their families in the process (Rosewilliam, Roskell, & Pandyan, 2011; Rosewilliam, Sintler, Pandyan, Skelton, &

Roskell, 2016b; Wressle et al., 1999). Specialists in rehabilitative services attributed the minimum inclusion of stroke survivors and their families in the goal-setting process to different barriers including time, dysfunctional therapeutic relationships, the patient's characteristics, the work environment and policies, families' goal agenda (which does not match the team's view), and assuming that all patients have similar goals (Maitra & Erway, 2006; Rosewilliam, Sintler, Pandyan, Skelton, & Roskell, 2016; Schulman-Green, Naik, Bradley, McCorkle, & Bogardus, 2006).

Since therapeutic goals, goal-setting process in the medical context, and involvement in clinical decision-making are complex and context-based processes (Bradley et al., 1999; Hersh et al., 2012a; Thompson, 2007), and since stroke and aphasia rehabilitation guidelines encourage cultural sensitivity when providing services to stroke survivors (Hebert et al., 2016; Stroke Foundation, 2010, 2017), there is a need to understand goal-setting from a wider perspective that encompasses individuals' unique culture. To address goal-setting in a way that optimises contextual transparency in research and cultural sensitivity in practice, a background to the context of participants' experience of stroke and aphasia is needed.

1.11 Research aims

The literature review in this chapter shows that the experience of stroke and aphasia, and views on aphasia therapeutic goals and goal-setting have been explored mainly in Europe, USA, Canada, and Australia. Because the literature revealed a lack of qualitative research on aphasia in Saudi Arabia, especially in the area of the experience of stroke and aphasia and goal-setting, there is a demand for conducting this research in the specific Saudi context. This research aims to contribute toward adding context-transparent research into aphasia literature, and also toward practicing context-sensitive approaches in rehabilitation.

Since the experience of stroke and aphasia in different cultures is valuable to clinical practice, therapeutic goal-setting is suggested to be context-based, and that the Saudi cultural context might differ from the ones reported in the literature, this study aims at exploring goal-setting in aphasia rehabilitation within the cultural context of stroke and aphasia experience from the viewpoints of PWA, their family members, and SLTs in Saudi Arabia by:

- Exploring and comparing the views of participant groups on the experience of stroke and aphasia for an in-depth understanding of the experience and its context.
- Exploring and comparing the views of participant groups on therapeutic goal-setting for aphasia for an in-depth understanding of the process.
- Conceptualising therapeutic goal-setting in aphasia rehabilitation based on participants' data, and by investigating related factors against the background of research context (the Saudi context of people's experience) and other contexts reported in the literature.

1.12 Thesis structure

In this thesis, chapter 2 provides an overview of the materials used in the study and how they were developed in order to serve the aims of the project. Then, chapter 3 presents selected analytical approach to adopt in the current study and justifications therefor. In addition to that, chapter 3 presents an overview of cross-language research and translation strategies reported in the literature, along with the selected method for the current study. Chapter 4 provides the methods followed in order to achieve the aims of the study, along with full details of the participants, design, and data collection procedure. In chapter 5, pilot studies that were conducted in order to examine the developed materials and selected analytical methods are reported. In chapter 6, a full, thorough account of the results (supported by rich extracts of participants' responses) is presented. Finally, chapter 7 presents a discussion of the findings in relation to the study context and other contexts reported in the literature, a conceptualisation of goal-setting, in addition to the final conclusion.

Chapter 2 Development of Research Materials

2.1 Introduction

Chapter 2 presents novel materials that were developed to collect data in the current study. The chapter starts by presenting a systematic review that was conducted in order to build interview schedules for collecting the views of PWA, their family members, and SLTs. Then, the chapter presents a section on developing a tool with which to collect data from the case records of PWA. The final part of this chapter provides information on developing aphasia-friendly materials that aimed to facilitate the communication of PWA during interviews.

2.2 Developing interview questions

To develop three evidence-based and research-led interview schedules for the three participant groups (PWA, their family members, and SLTs), a systematic review of the relevant research literature was conducted. The following sub-sections present the search strategies, data screening, a critical appraisal of studies, data analysis and rigour, and the designing of interview schedules.

2.2.1 Search strategies

2.2.1.1 Locating the evidence

To achieve the aim of the current study, interview questions for all participant groups were developed after a systematic review of the literature. The aim was to develop a set of evidence-based and research-informed questions including questions on the experience of stroke and aphasia, and goal-setting in aphasia therapy. Initial scoping of qualitative literature on aphasia showed that most studies automatically included questions about the experience of stroke and aphasia when interviewing PWA in order to set the scene for the interview. However, questions on goal-setting were less frequently reported in the literature. Questions about the experience of stroke and aphasia were frequently reported in the literature of therapeutic goals to prepare PWA to answer more detailed questions (e.g. Howe et al., 2012; Rohde, Townley-O'Neill, Trendall, Worrall, & Cornwell, 2012; Sherratt et al., 2011; Worrall et al., 2011). Since there was a need to access both areas using a systematic method, one systematic review was conducted to access both questions on the experience of stroke and aphasia, and goal-setting.

Since questions on goal-setting were less reported in the literature of aphasia, studies that interviewed participants with different neurological conditions who were receiving rehabilitative services were included. This decision was made because neurological rehabilitation in general also encompasses post-stroke aphasia therapy. This decision was also based on the assumption that PWA and other individuals with neurological conditions might share some similar features regarding communication difficulties, might have common goals in therapy, or could be receiving similar rehabilitative services.

The literature searches were conducted on the 19th and 20th of May 2017 using the following databases: Scopus, Web of Science, Medline via Ovid, and ProQuest Education Journals. Keywords were determined based on their relevance to the main topic being explored, and also based on most commonly used terms in the literature of qualitative research on aphasia and goal-setting. The following combinations were used to retrieve records from the databases: ("goal-setting" AND aphasia), ("goal-setting" AND stroke AND interviews), ("goal-setting" AND aphasia AND interviews), ("goal-setting" AND aphasia AND qualitative), ("goal-setting" AND rehabilitation AND qualitative), and ("goal-setting" AND rehabilitation AND interviews). The term "rehabilitation" was used to search for studies in the literature that used qualitative interviews with participants who were undergoing rehabilitation and experiencing neurological conditions other than aphasia. The terms “aphasia”, “stroke”, “interviews”, and “qualitative” were used in combination with “goal setting” to search for studies that reported interview questions about goal-setting and also opening questions on experiencing and living with stroke and aphasia. Table 2.1 provides details of the keyword combinations and the rationale behind using them.

Table 2.1 Search keyword combinations and rationale

Keywords	Keyword combinations	Rationale
“Goal setting” “Aphasia” “Stroke” “Interviews” “Qualitative” “Rehabilitation”	“Goal setting” AND aphasia	To retrieve documents that investigated goal-setting in the area of aphasia.
	“Goal setting” AND rehabilitation AND qualitative	To retrieve documents that used qualitative methods, including interviews, to investigate goal-setting in the area of rehabilitation. This was done to ensure retrieving qualitative documents that might not have used the term “interviews” in their abstract, title or keywords.
	“Goal setting” AND aphasia AND qualitative	To retrieve documents that used qualitative methods, including interviews, to investigate goal-setting in the area of aphasia. This was done to ensure retrieving qualitative documents that might not have used the term “interviews” in their abstract, title or keywords.
	“Goal setting” AND rehabilitation AND interviews	To retrieve documents that specifically used interviews as a method through which to investigate goal-setting in the area of rehabilitation with a wide range of medical conditions.
	“Goal setting” AND stroke AND interviews	To retrieve documents that specifically used interviews as a method through which to investigate goal-setting in the area of stroke. This was done also to retrieve goal-setting studies that used interviews to ask about stroke experience.
	“Goal setting” AND aphasia AND interviews	To retrieve documents that specifically used interviews as a method through which to investigate goal-setting in the area of aphasia. This was done also to retrieve goal-setting studies that used interviews to ask about aphasia experience.

The initial search attempt in the aforementioned databases yielded 3663 results. These results were saved in citation manager Mendeley, which assists in retrieving, saving and managing references. Table 2.2 provides the details of search terms used keywords, databases, and the number of results.

Table 2.2 Database search results

Term combinations	**Scopus**	**Medline via Ovid**	**Web of Science**	**ProQuest Education Journals**
"Goal setting" AND aphasia	21	16	19	134
"Goal setting" AND aphasia AND interviews	7	436	9	61
"Goal setting" AND aphasia AND qualitative	9	183	10	75
"Goal setting" AND stroke AND interviews	36	777	39	452
"Goal setting" AND rehabilitation AND interviews	105	67	104	379
"Goal setting" AND rehabilitation AND qualitative	89	128	90	417
	267	1607	271	1518
Total results: 3663 **Duplicates: 1390** **Results after deleting duplicates: 2273**				

2.2.1.2 Inclusion criteria and exclusion criteria

Certain criteria were predetermined so as to include and exclude studies for later analysis. Study articles were included for further exploration if they met the following criteria:

- Studies must be published in English.
- Studies must be between the years 1990 and 2017. This date limit was chosen so as to achieve a balance of retrieving a wide yet recent range of records. Systematic reviews in the literature that have investigated topics of aphasia and stroke have used similar date ranges of 10–30 years (e.g. Rohde, Worrall, & Le Dorze, 2013; Rosewilliam, Roskell, & Pandyan, 2011; Simmons-Mackie & Lynch, 2013).
- Participants of the studies must be adults with neurological conditions receiving rehabilitative services, and/or their family members, and/or their therapists.
- Studies must have used interviews or focus groups as a method of qualitative data collection.
- Participants must be involved in the interviews or focus groups.
- Interview or focus group questions and/or topics must focus on, or include a section on, goal-setting and/or therapeutic goals.
- Studies must have reported the interview or focus group questions and/or topics.

Studies were excluded from the review if they met one or more of the following criteria:

- Books, book chapters, reviews of existing data, and conference reports.
- Studies that used purely quantitative methods and outcome measures.
- Studies that did not investigate goal-setting or goals or did not have a section on goals.
- Studies that did not report the details of interview questions or topics.
- Studies that were not available in the form of full texts.

2.2.2 Data screening

In this stage of record screening, two researchers were involved in order to enhance the reliability of the process. The main researcher and a second researcher from the research group (First supervisor) independently screened all included records at each stage (title, abstract, full text) using the inclusion and exclusion criteria reported previously.

At each stage after the records have been screened independently by each researcher, the two record sets were cross-checked. Records that were considered to meet the criteria by both researchers independently were included automatically in the next stage of screening. Records that only one researcher had selected were considered by both researchers again, and agreement as to whether the item should be included or excluded was determined via discussion.

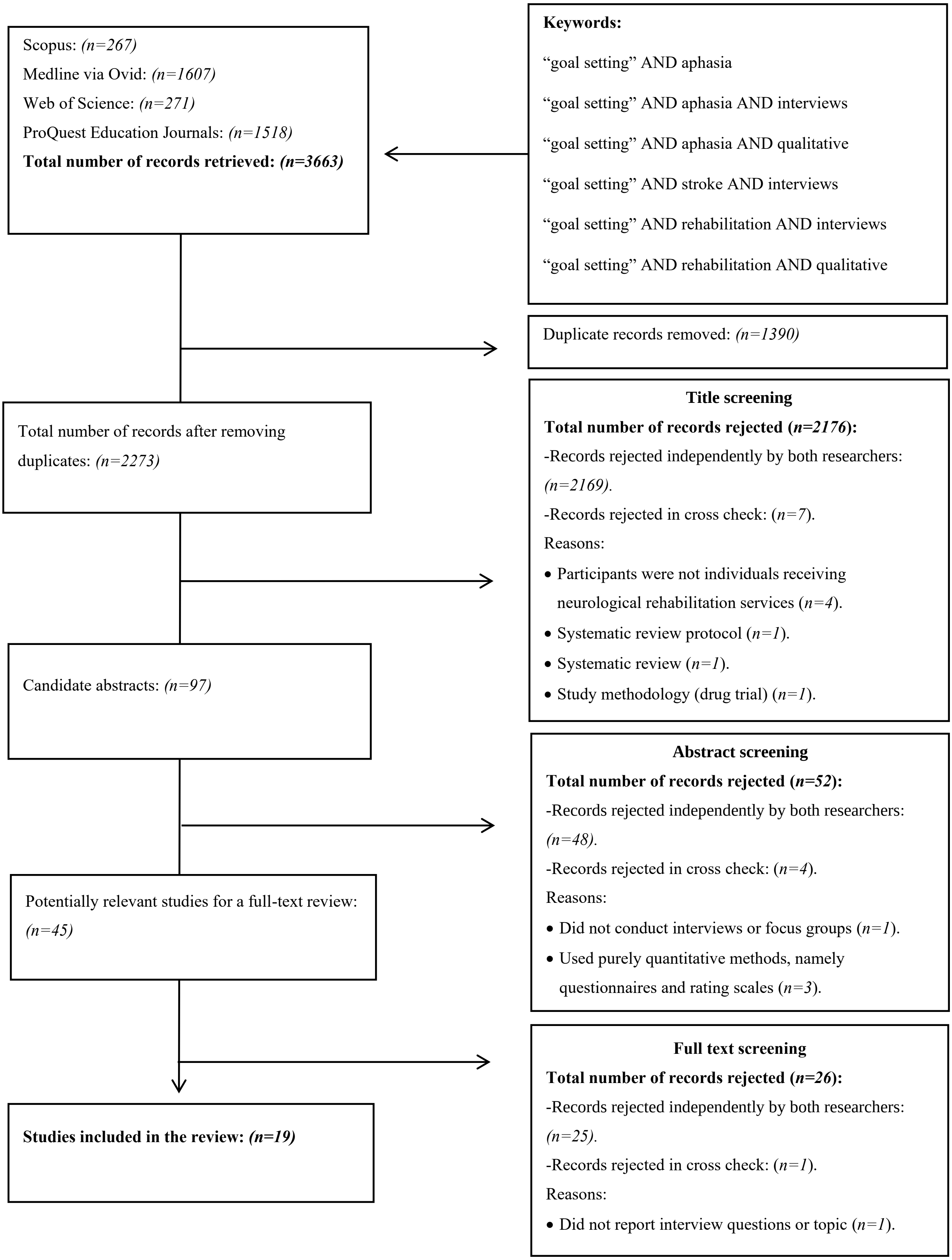
Where it was not clear as to whether a record met the criteria, this item was included and screened in the next stage. In the stage of title screening, the researchers took into consideration that some titles might not include the keywords “goal setting”, yet the records might have included sections on goal setting. Therefore, if there was a possibility that a certain record included sections on goal setting, these were considered by the researcher for inclusion in the next phase, if appropriate.

After the retrieval of records, 1390 duplicates were removed, which resulted in 2273 records. Thereafter, the aforementioned inclusion and exclusion criteria were utilised in order to screen the set of 2273 records and discard those which did not match the criteria. The titles and abstracts of the 2273 records which entered this stage were retrieved and reviewed in line with the exclusion and inclusion criteria. This resulted in the exclusion of 2176 studies based on the title. From the remaining 97 studies, 52 were excluded based on the abstract. It was possible to exclude studies based on the title where, for example, the title named the participant group explicitly and it was clear that this group did not meet the inclusion criteria (e.g. children, adult alcohol addicts), or documents being literature and systematic reviews with no original data. With regard to studies that were excluded based on the abstract, studies that did not use interviews or focus groups or that used purely quantitative methods were excluded. This resulted in the inclusion of 45 studies for full-text review. The remaining 45 studies were screened using the same inclusion and exclusion criteria. This process led to the exclusion of 26 studies on the grounds that the participants and methods did not fit the inclusion criteria or that studies did not report the interview questions or topics used. The screening process resulted in the inclusion of 19 studies in the critical appraisal process. Figure 2.1 shows the full data retrieval process, and Appendix A shows a table of the included studies.

2.2.3 Critical appraisal of studies

Studies included in this systematic review were next critically appraised for methodological quality. Various qualitative appraisal tools are available in the literature; these include: Popay, Rogers, and Williams (1998), the Critical Appraisal Skills Programme (2017), the Quality Framework (2003).

Other tools are also available including Prompts for Appraising Qualitative Research (2004), Long and Godfrey (2004), and Walsh and Downe (2006) (Centre for Reviews and Dissemination, 2009). For the current project, the Critical Appraisal Skills Programme (CASP) (2017) instrument was adopted in order to evaluate the study articles included. The CASP (2017) was chosen because it is an updated, thorough and practical tool that includes 10 questions aiming to evaluate the rigour, credibility and relevance of studies.



Scopus: *(n=267)*
Medline via Ovid: *(n=1607)*
Web of Science: *(n=271)*
ProQuest Education Journals: *(n=1518)*
Total number of records retrieved: *(n=3663)*

Keywords:

"goal setting" AND aphasia

"goal setting" AND aphasia AND interviews

"goal setting" AND aphasia AND qualitative

"goal setting" AND stroke AND interviews

"goal setting" AND rehabilitation AND interviews

"goal setting" AND rehabilitation AND qualitative

Duplicate records removed: *(n=1390)*

Total number of records after removing duplicates: *(n=2273)*

Title screening

Total number of records rejected (*n=2176*):

-Records rejected independently by both researchers: *(n=2169).*

-Records rejected in cross check: (*n=7*).

Reasons:

- Participants were not individuals receiving neurological rehabilitation services (*n=4*).
- Systematic review protocol (*n=1*).
- Systematic review (*n=1*).
- Study methodology (drug trial) (*n=1*).

Candidate abstracts: *(n=97)*

Abstract screening

Total number of records rejected (*n=52*):

-Records rejected independently by both researchers: *(n=48).*

-Records rejected in cross check: (*n=4*).

Reasons:

- Did not conduct interviews or focus groups (*n=1*).
- Used purely quantitative methods, namely questionnaires and rating scales (*n=3*).

Potentially relevant studies for a full-text review: *(n=45)*

Full text screening

Total number of records rejected (*n=26*):

-Records rejected independently by both researchers: *(n=25).*

-Records rejected in cross check: (*n=1*).

Reasons:

- Did not report interview questions or topic (*n=1*).

Studies included in the review: *(n=19)*

Figure 2.1 Overview of data retrieval process

For each question, three answer options are available: “yes”, “no”, and “can’t tell”, in addition to the “HINT”, which are points to consider when answering the questions written in bullet points. In the CASP (2017), the first two questions are screening questions, which means that if the answer to both of them is “yes”, then the researcher should continue to answer the remainder of the questions.

When all included studies were evaluated, the answers to the first two questions were “yes”; thus, no studies were excluded from the quality appraisal. For the remainder of the questions, the answers included “yes”, “no”, and “can’t tell”. Comments were added in some cells so as to justify or clarify the answers. For instance, when Al-Haidary et al.'s (2015) study was evaluated, the third question — “Was the research design appropriate to address the aims of the research?” — was answered with “yes”, and the following comment was added: “Not clear how interview questions were developed.” This was undertaken because the overall design of Al-Haidary et al.’s (2015) study was appropriate, but a specific area was unclear. Appendix B presents the complete evaluation of the studies using the CASP (2017) checklist.

2.2.4 Data extraction and analysis

At this stage, the main aim was to extract and analyse data regarding the interview questions and discussion topics from the 19 studies included. To cover all aspects presented in the literature and reported in the studies included, study outcomes were also investigated so as to explore whether new related topics emerged. Noyes and Lewin (2011) reported that extracting data from existing studies is a systematic process, and that the data extraction template should be designed to serve the purpose of the study. For that reason, the data extraction designed and used in the current project to collect information from the 19 included studies contained the following sections based on Noyes and Lewin (2011) recommendations:

-Study.

-Setting and context.

-Aim.

-Participants.

-Design and data collection methods.

-Interview questions or topics.

-Analysis methods.

-Findings and key themes.

-Quality of the study.

Please refer to Appendix C for an example of a filled form. A thematic analysis approach was adopted at this stage in order to analyse data without a pre-existing coding frame; thus, data analysis at this stage was inductive and data-driven (Braun & Clarke, 2006). Interview questions and discussion topics of the 19 studies included were identified within each study, coded, and categorised into possible themes.

Braun and Clarke's (2006) thematic analysis approach was selected because it provides systematic steps of thematic analysis. The adopted thematic analysis approach suggested by Braun and Clarke (2006) includes six steps. These include data familiarisation, code generation, theme searching, theme reviewing, naming and defining themes, and developing the final report.

As Braun and Clarke (2006) recommended, interview questions of the studies included were identified, copied, and pasted into a table in a Microsoft Word document. An additional column in the table was created in order to add statements of topics raised in the discussion or results section of the studies included that were related to goals and the process of setting them. This step was undertaken in order to ensure that this systematic review covers not only a wide range of topics raised in the interview questions, but also topics that emerged during the interviews. All data were read carefully and assigned initial codes manually. After all data were coded, a first review of data units and codes was conducted. In this initial review, some modifications were conducted, including segmenting initial codes (e.g. “Barriers” from “Goal-setting process”). Data were reviewed for a second time at the level of the entire dataset and the level of coded data extracted. Some modifications were undertaken again, including editing a code’s name (e.g. “Intervention goals” modified to “Practised goals” and then to “Current therapeutic goals”) and segmenting a code (e.g. “Experience” modified to “Experience with condition” and “Experience with services”). For the purpose of this project, and to manage data visually with the aim of developing novel interview questions, interview questions of the studies included were categorised into the assigned codes, and then tabulated. Study outcomes were categorised into the assigned codes, and tabulated also. Appendix D presents assigned codes of studies included in the systematic review.

After assigning codes, the process of searching for themes started. Codes and data were read in order to search for coherent patterns, and candidate themes were established. Afterwards, themes were reviewed multiple times and modified (e.g. “Personal aspects” modified to “Physical and emotional aspects” and to “The medical condition”). When all data were coded and themes were established, a final review of all coded data was conducted in relation to the themes. Table 2.3 presents an example of the thematic analysis process.

2.2.5 Analysis rigour

In qualitative research, credibility and dependability are two aspects that refer to internal validity and reliability, respectively.

Table 2.3 An example of thematic analysis process

Study references	Interview questions, topics, or outcome statements	Sub-code	Codes	Themes
	Interview topics related to interviewing stroke survivors and their family members:			The medical condition
7. Howe, T., Davidson, B., Worrall, L., Hersh, D., Ferguson, A., Sherratt, S., & Gilbert, J. (2012).	"The participants' experience of having a family member with aphasia"	Experience of having a close relative with a medical condition.	Experience with the condition	
10. Lawler, J., Dowswell, G., Hearn, J., Forster, A., & Young, J. (1999).	"The interview explored the impact of stroke,.."	The impact of the medical condition.	Experience with the condition	
	Outcome statements related to interviewing healthcare professionals:			The practice of goal-setting in rehabilitation
17. Schulman-Green, D. J., Naik, A. D., Bradley, E. H., McCorkle, R., & Bogardus, S. T. (2006).	"In contrast, clinicians reported that goal discussions are particularly helpful when conducted at a first visit with patients to get to know them better."	Discussing goals early is beneficial to reducing later conflicts.	The involvement of others in goal-setting	

15. Rohde, A., Townley-O’Neill, K., Trendall, K., Worrall, L., & Cornwell, P. (2012).	***Questions directed towards patients:*** What was important to you then? Now?	Patient’s desired goals at an early stage/ Patient’s desired goals at present.	Desired goals	
16. Rosewilliam, S., Sintler, C., Pandyan, A. D., Skelton, J., & Roskell, C. A. (2016).	What are your current needs in the hospital?	Patient’s desired goals at present.	Desired goal	

Credibility, or ensuring the accuracy of what the researcher aimed to detect, and dependability, or ensuring consistency in similar contexts (Shenton, 2004), were enhanced through the adoption of different strategies during the process of data analysis. As Gibbs (2007) suggested, credibility was enhanced via constant comparisons in which data were checked multiple times for coding consistency and accuracy.

As suggested in the literature, 10% of the sample was double-coded (Campbell, Quincy, Osserman, & Pedersen, 2013; Hodson, 1999). Since the total number of studies included was 19, three studies were randomly selected and given to another PhD researcher to be coded.

The agreement percentage of coding interview questions and topics between the two researchers reached 91%. The researcher discussed points of disagreement with colleague, and reached an agreement on current data coding. With regard to agreements between coders, the literature provides some guidance on the satisfactory percentage range but does not confirm a specific threshold. What researchers consider to be acceptable regarding coding reliability depends on the researchers' standards, the content analysed, and the calculation method (Campbell, Quincy, Osserman, & Pedersen, 2013). A correlation of 79 was reported in the literature to be considered a high degree of reliability (Hodson, 1999), and a range of 70–94% was reported to be acceptable to exceptional (Fahy, 2001). Campbell, Quincy, Osserman, and Pedersen (2013) reported that they aimed for 80–90% for intercoder reliability, while Kurasaki (2000) accepted 70% during training and 94% during the main coding process. Therefore, the agreement percentages in this study was deemed to be acceptable.

2.2.6 Analysis results

Thematic analysis resulted in three main themes presented in Figure 2.2 which represent main areas that were discussed with participants in studies available in the literature of goal-setting that included also questions on experiencing the medical condition. The three themes that emerged after data analysis were “The medical condition”, “The practice of goal-setting in rehabilitation”, and “Rehabilitation experience and outcome”.

The theme of “The medical condition” covered the following codes: “Experience with condition” and “Communication skills”. This theme emerged from the discussion of topics related to participants’ experience with the medical condition. The theme covered interview questions and topics on physical skills and the impacted areas by the medical condition. The theme of “The practice of goal-setting in rehabilitation” covered the following codes: “Current therapeutic goals”, “Desired goals”, “Goal definition”, “Goal-setting process”, “The involvement of others in goal-setting”, and “Factors influencing effective/collaborative goal-setting”. This theme emerged from interview topics and questions related participants’ current therapeutic goals and their hopes, the process of goal-setting in rehabilitation, and the involvement if others in the process. The last theme of “Rehabilitation experience and outcome” emerged from the following codes: “Experience with services”, “Satisfaction”, “Progress”, and “Patient and family involvement in rehabilitation”. This theme is related to the overall experience and approach of rehabilitation, in addition to satisfaction with therapy. The theme also relates to the progress observed by interviewees in relation to their skills.

Table 2.4 presents included studies, codes and themes, and Table 2.5 presents all themes, specific codes, and examples of the interview questions from the studies analysed.

2.2.7 Designing the interview schedules

The interview schedule is a necessary component of semi-structured interviews because it allows the researcher to follow a consistent procedure.

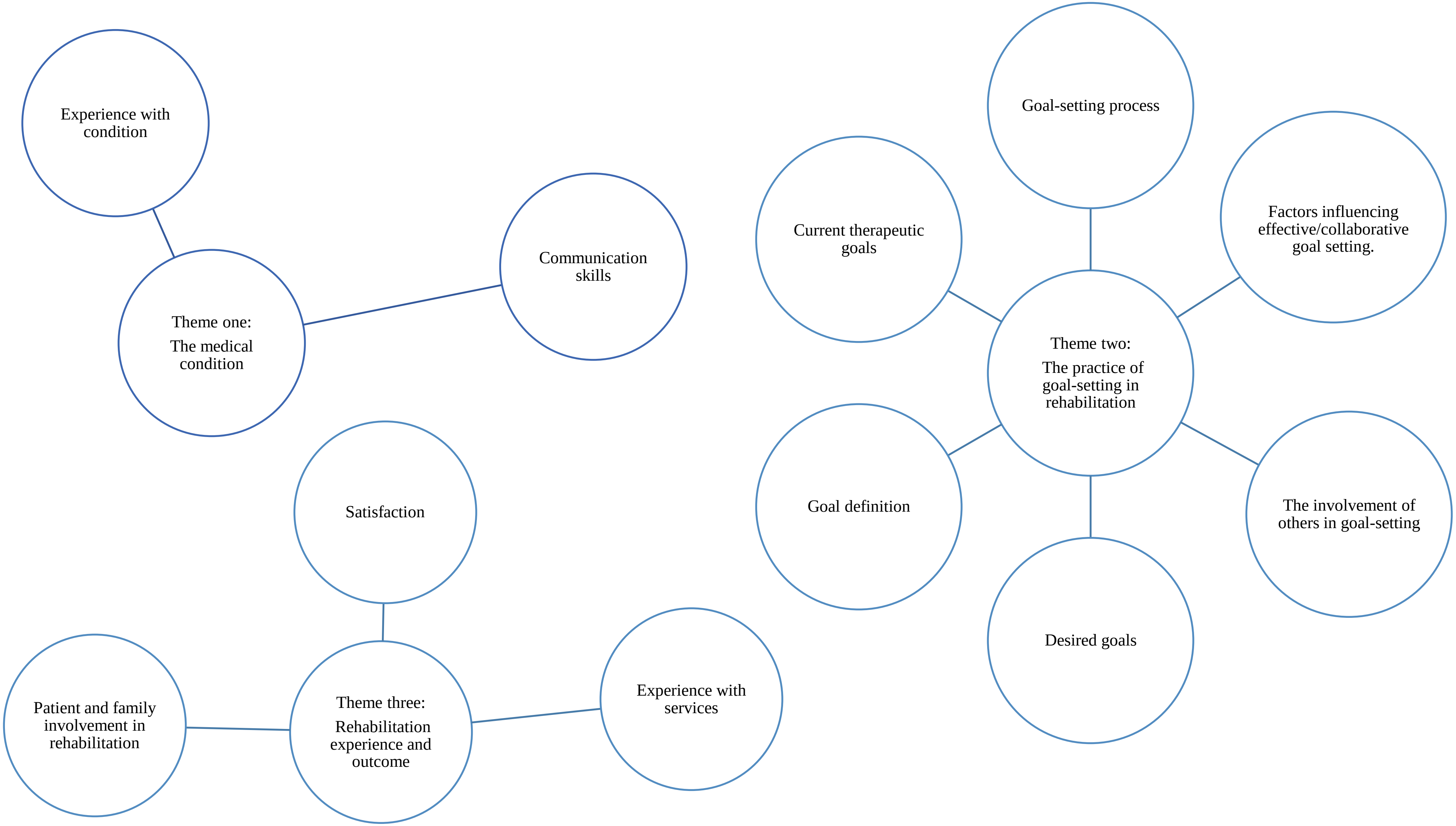


Figure 2.2 Themes and codes emerged from included studies

Table 2.4 Included studies, themes, and codes

Participant group	Studies	Themes and codes
Individuals with medical conditions	15. Rohde, A., Townley-O'Neill, K., Trendall, K., Worrall, L., & Cornwell, P. (2012). 14. Power, E., Anderson, A., & Togher, L. (2011). 1. Al-Haidary, H., Qannam, H., & Lam, T. (2015). 6. Holliday, R. C., Ballinger, C., & Playford, E. D. (2007). 16. Rosewilliam, S., Sintler, C., Pandyan, A. D., Skelton, J., & Roskell, C. A. (2016). 9. Laver, K., Halbert, J., Stewart, M., & Crotty, M. (2010). 2. Baird, T., Tempest, S., & Warland, A. (2010). 19. Worrall, L., Sherratt, S., Rogers, P., Howe, T., Hersh, D., Ferguson, A., & Davidson, B. (2011). 10. Lawler, J., Dowswell, G., Hearn, J., Forster, A., & Young, J. (1999). 12. Maitra, K. K., & Erway, F. (2006). 17. Schulman-Green, D. J., Naik, A. D., Bradley, E. H., McCorkle, R., & Bogardus, S. T. (2006). 3. Berg, K., Askim, T., Balandin, S., Armstrong, E., & Rise, M. B. (2017). 4. Conneeley, A. L. (2004)	**The medical condition:** -Experience with condition -Communication skills **The practice of goal-setting in rehabilitation:** -Current therapeutic goals -Desired goals -"Goal" definition -The involvement of others in goal-setting -Goal-setting process -Factors influencing effective/collaborative goal-setting **Rehabilitation experience and outcome:** -Experience with services -Satisfaction -Progress
Family members/ caregivers	7. Howe, T., Davidson, B., Worrall, L., Hersh, D., Ferguson, A., Sherratt, S., & Gilbert, J. (2012). 14. Power, E., Anderson, A., & Togher, L. (2011). 10. Lawler, J., Dowswell, G., Hearn, J., Forster, A., & Young, J. (1999). 4. Conneeley, A. L. (2004)	**The medical condition:** Experience with condition Communication skills **The practice of goal-setting in rehabilitation:** Desired goals **Rehabilitation experience and outcome:** Experience with services Patient and family involvement in rehabilitation
Clinicians	18. Sherratt, S., Worrall, L., Pearson, C., Howe, T., Hersh, D., & Davidson, B. (2011). 15. Rohde, A., Townley-O'Neill, K., Trendall, K., Worrall, L., & Cornwell, P. (2012). 16. Rosewilliam, S., Sintler, C., Pandyan, A. D., Skelton, J., & Roskell, C. A. (2016). 5. Hersh, D., Sherratt, S., Howe, T., Worrall, L., Davidson, B., & Ferguson, A. (2012a). An analysis of the "goal" in aphasia	**The practice of goal-setting in rehabilitation:** -Current therapeutic goals -"Goal" definition -Desired goals -Goal-setting process -The involvement of others in goal-setting -Factors influencing effective/collaborative goal-setting

	10. Lawler, J., Dowswell, G., Hearn, J., Forster, A., & Young, J. (1999). 11. Levack, W. M. M., Siegert, R. J., Dean, S. G., & McPherson, K. M. (2009). 12. Maitra, K. K., & Erway, F. (2006). 17. Schulman-Green, D. J., Naik, A. D., Bradley, E. H., McCorkle, R., & Bogardus, S. T. (2006). 8. Kuipers, P., Carlson, G., Bailey, S., & Sharma, A. (2004). 13. Parsons, J. G. M., Plant, S. E., Slark, J., & Tyson, S. F. (2016). 4. Conneeley, A. L. (2004)	**Rehabilitation experience and outcome:** -Experience with services -Satisfaction -Patient and family involvement in rehabilitation -Progress

Table 25. Themes and examples of coded questions from the literature

Themes / Participant group	The medical condition	The practice of goal-setting in rehabilitation	Rehabilitation experience and outcome
Individuals with medical conditions	**Experience with condition** "In what ways has the stroke affected you?" (Rosewilliam, Sintler, Pandyan, Skelton, & Roskell, 2016) **Communication skills** "What communication situations do you most enjoy/are most frustrating?" (Power, Anderson, & Togher, 2011)	**Desired goals** "What would you like to achieve by working with speech pathology?" (Schulman-Green, Naik, Bradley, McCorkle, & Bogardus, 2006) **Current therapeutic goals** "What are you doing in speech pathology now? What are you targeting?" (Berg, Askim, Balandin, Armstrong, & Rise, 2017) **Goal definition** "Before you came here, what would have been your first thoughts on hearing the word 'goal'?" (Holliday, Ballinger, & Playford, 2007) **The involvement of others in goal-setting**	**Progress** "What factors do you think will help you to make further recovery?" (Laver, Halbert, Stewart, & Crotty, 2010) **Experience with services** "The interview explored ……, the services received and their relative value to the patient/caregivers, ……" (Lawler, Dowswell, Hearn, Forster, & Young, 1999). **Satisfaction** "To what extent are you satisfied with your occupational therapy experience thus far?" (Maitra & Erway, 2006)

		“Were clear rehabilitation goals set, discussed and/or communicated to/with you?” (Al-Haidary et al., 2015) “What were your feelings about it?” (Holliday et al., 2007) **Factors influencing effective/collaborative goal-setting** “What factors make goal-setting difficult?” (Baird, Tempest, & Warland, 2010)	
Family members/caregivers	**Experience with condition** “The following topics were used to guide the interviews: the participants’ experiences of having a family member with aphasia, ……” (Howe et al., 2012). **Communication skills** “Tell me about what communication is like for you/and ER now.” (Power et al., 2011)	**Desired goals** “The following topics were used to guide the interviews: ……, their rehabilitation goals and needs, …….” (Howe et al., 2012).	**Experience with services** “The interview explored ……, the services received and their relative value to the patient/caregivers, ……” (Lawler et al., 1999).

Clinicians		**Current therapeutic goals** “What are you doing with this patient? Why?” (Rosewilliam et al., 2016) **Goal definition** “How would you define a goal?” (Sherratt et al., 2011) **Desired goals** “What do you think the person’s goals were?” (Sherratt et al., 2011) **The involvement of others in goal-setting** “Tell me about involving families and carers in goal-setting.” (Levack, Siegert, Dean, & McPherson, 2009) **Factors influencing effective/collaborative goal-setting** “What is that within you that stops you from contributing to setting patient centred goals?” (Rosewilliam et al., 2016)	**Progress** “How were these goals used in monitoring progress?” (Lawler et al., 1999) **Experience with services** “When did therapy start? Tell me about your early impressions.” (Rohde, Townley-O’Neill, Trendall, Worrall, & Cornwell, 2012) **Patient and family involvement in rehabilitation** “Tell me about your involvement with person with aphasia and his family.” (Sherratt et al., 2011) **Satisfaction** “Later section of the interview schedule covered the nurses’ views of the effectiveness of their interventions and their views on how effectively patients adjust to their changed circumstances.” (Lawler et al., 1999)

Thus, interview schedules add a level of standardisation and enhance the rigour of the research. Kvale (2007) advised that interview questions be simple and brief. In addition, leading questions are not preferably used in qualitative interviews unless they serve the purpose of verifying answers.

After conducting the systematic literature review reported previously, and extracting data from the studies included, a total of three interview schedules were developed for the purpose of the current project. These schedules were prepared in advance so as to guide the researchers while interviewing PWA, their family members, and SLTs. Interview guides for each participant group included the same sequence of questions, a space between the questions in which to record notes, a space on the side in which to record general field notes if needed, and comments for reminding the researcher to brief and debrief (Creswell, 2007).

Interview guides were designed based on data extracted from the literature. The questions developed covered all aspects that emerged from the systematic review conducted; thus, questions covered major areas reported in the literature on goal-setting in rehabilitation. Since the aim of the project is to investigate the experience of stroke and aphasia, as well as goal-setting from three viewpoints (PWA, their family members, and SLTs), it was necessary to address the same topics in the three interview schedules. Figure 2.3 provides an overview of how novel questions were developed after reviewing the literature.

First, the emerging themes and all codes were read. Furthermore, questions of the studies included were read in order to grasp a sense of the question design. Then, themes and codes were copied and pasted into three separate Microsoft Word documents for the purpose of organising novel questions within them.

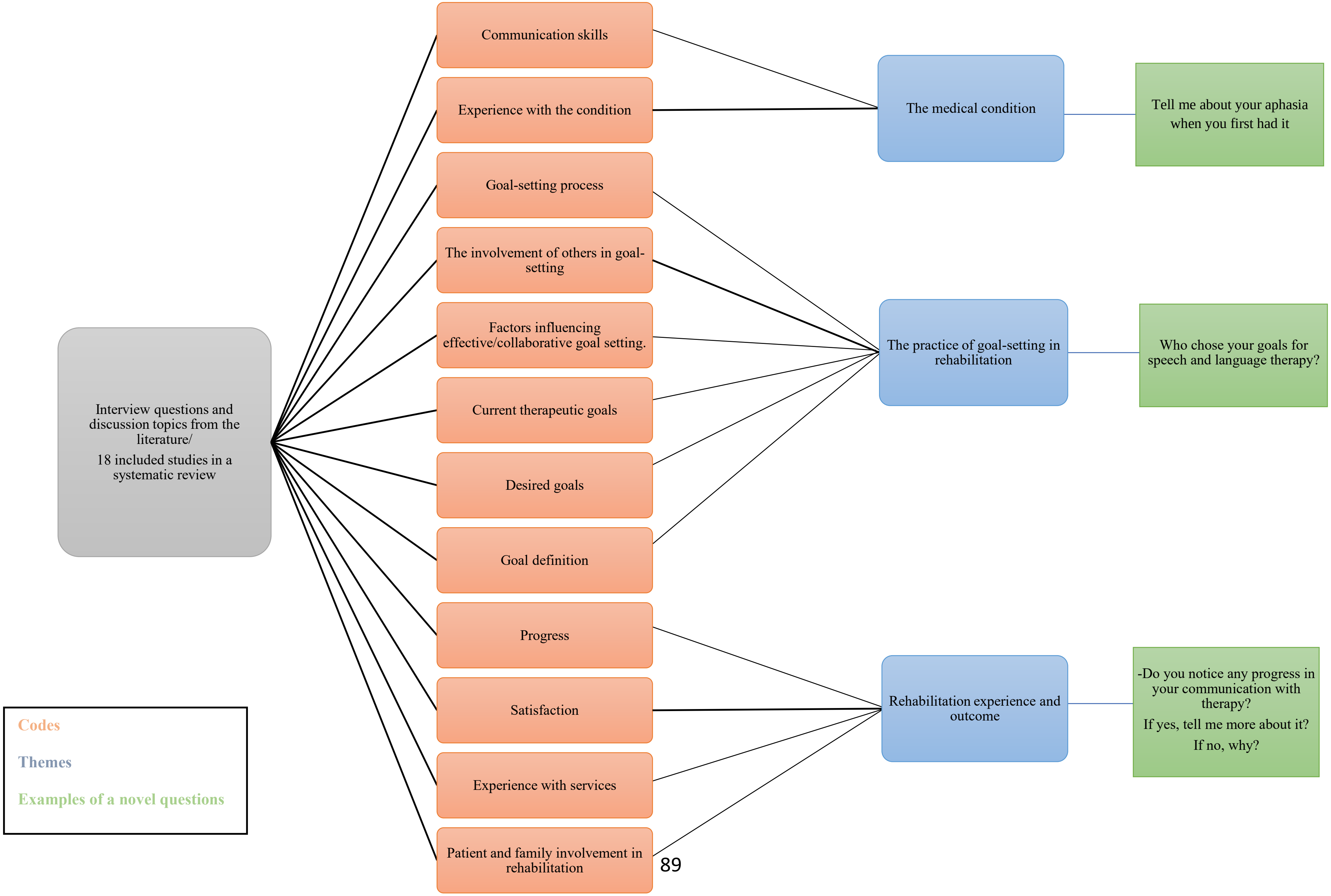


Figure 2.3: Overview of how novel questions were developed

A list of initial questions was developed for each participant group. Question lists were reviewed by the main researcher multiple times and modified so as to fit the purpose of the project.

While developing the interview schedules, it was considered appropriate by the researcher to organise novel questions within codes (instead of their themes) for the purpose of sequencing from general questions about the experience of the condition and services to specific questions (e.g. the participation in goal-setting). For example, the theme of "Rehabilitation experience and outcome" included questions on experience with services, progress, and overall involvement in rehabilitation. However, it was not considered appropriate by the researcher to ask these questions consecutively. It was considered more appropriate to ask about the general experience with services at the beginning to prepare moving to the context of goal-setting, and then to ask about the progress at the end to understand participants' views on the outcome of therapy. Interview schedules started with general questions on the topic of aphasia; afterwards, questions were narrowed down so as to talk about goals and needs in order to allow participants to process their experience easily, which was similar to the approach adopted by Howe et al. (2012), Sherratt et al. (2011) and Worrall et al. (2011). Questions were open-ended (e.g. "Tell me about your aphasia when you first had it"), and when yes/no questions were asked, clarification probes were used (e.g. "Did you help your SLT to choose what to work on in therapy sessions? If yes, tell me how; if no, tell me why").

Interview questions for the three participant groups covered all themes manifested after the systematic review of the literature. However, some slight variations were considered from one participant group to another. For example, PWA and their families were not asked directly about the definition of a "goal", as this might have been an abstract concept for them to define and think about. Furthermore, PWA and their families were not asked about their satisfaction with services. Satisfaction was avoided, as not to pressure participants to evaluate services that they currently receive, and with the potential fear that this would affect their therapy or their relationship with the therapist. With regard to SLTs, this group were not asked about experience with the condition, as this topic was directed specifically towards PWA and their families. Moreover, SLTs were not asked about their satisfaction with their therapy or patients' progress in order to avoid their having to judge their own skills and knowledge. Initial questions that were piloted are presented in Appendix E, and the final version of questions with rationales are presented in Appendix F.

2.3 Developing a case record data extraction tool

In the following sub-sections, an overview of studies that reported collecting data from clinical records is presented. Then, recommendations on developing a case record data extraction tool are presented as evidenced in the literature, and details on designing a tool with which to collect data from PWA's records in the current project are reported.

2.3.1 Overview of studies

Williams, Kingham, Morgan, & Davies (1990) reported that clinical case records are valuable for clinical audit. Different medical studies in the area of stroke have reported extracting information from stroke survivors' records as a method of data collection (Eze, Ezemba, & Adamu, 2010; House, Dennis, Hawton, & Warlow, 1989; Imam & Olorunfemi, 2005; Mackenzie, Paton, Kelly, Brady, & Muir, 2012; Mohammed, Nur, Kurashi, Ibrahim, & Ammar, 1996; Qari, 2001; Lesley Scobbie, McLean, Dixon, Duncan, & Wyke, 2013a).

In these studies, patients' case records were reviewed in order to collect specific predetermined information including stroke survivors' demographic information, medical history, and intervention goals. Studies that explored the experience of stroke and aphasia have not reported the use of case records for purposes other than collecting demographic information of participants (e.g. Chen, Xiao, & De Bellis, 2016; Parr, 2001).

In addition to collecting demographic information, researchers who studied goal-setting used case records also to collect documented data about therapeutic gaols. To provide examples of studies in the area of therapeutic goals and the process of goal-setting, Simpson, Foster, Kuipers, Kendall, & Hanna (2005) conducted a study to investigate and compare goals set in two different brain injury rehabilitation services in Australia. As part of their method, they examined patients' files after ethical approval and consent, and then extracted goal statements, transcribed them verbatim, and categorised them according to a pre-developed list. Rosewilliam, Sintler, Pandyan, Skelton, & Roskell (2016) investigated the goal-setting process in an acute stroke unit in the UK, using patients' case records to extract data from events including goal-planning meetings. They also collected and summarised data reported by healthcare professionals with regard to patients' goals and rehabilitation plan. Scobbie et al. (2013) developed a goal-setting and action planning framework (G-AP) to guide healthcare professionals when setting goals through four stages. Patients' case notes were examined in order to check the accuracy of adopting the G-AP in goal-setting. Laver et al. (2010) examined participants' progress records, and statements in relation to goals were documented and used as data. The researchers reported that the data extracted from progress notes were analysed individually and in relation to the data collected from interviews.

Although the abovementioned studies have reported the exploration of stroke survivors' case record, information on how these data were extracted and analysed was not reported in sufficient so as to allow for adopting a systematic methodology for the current project.

This indicates that the researchers designed the tool according to the aims of their project, and analysed the collected data by adopting a method that also facilitated achieving the project aims. Therefore, for the current study, a case record data extraction form was designed to serve the purpose of the study according to available recommendations available in the literature.

2.3.2 Recommendations to design a case record data extraction tool

Recommendations to guide researchers to collect data from case records were presented in qualitative research literature. In their study of clinical audit, Williams, Kingham, Morgan, and Davies (1990) reported that the process of extracting data from patients' records should be pre-planned. Thus, the type of data should be defined clearly, categories of possible answers need to be stated (i.e. yes, no, not reported in the record). Hatry (1994) provided recommendations on collecting data from documents in qualitative research. Hatry (1994) recommendations include contacting directly the person in charge of the case records to facilitate faster accessibility of data, and also using computer software to manage data if needed. Moreover, individuals' names should not be recorded when collecting their data; their assigned codes should be documented instead. Names and assigned codes should be documented in a separate list, saved securely, and then destroyed when the aim of the project is achieved. In addition to that, evaluation data should not be collected from individuals' records unless a permission was granted for that purpose (Hatry, 1994).

2.3.3 Designing a case record data extraction tool

For the purpose of this project, and to achieve the research aims, three categories of data were identified to be collected: participants' demographic information, participants' medical information, and speech and language therapy information. Including demographic information in the form is necessary in order to collect background information on participants.

Participants' medical information, which included information on aphasia, stroke, and comorbid conditions, was an essential section to include because of the need to understand participants' medical status in relation to therapy and goal-setting. The final section, which comprises speech and language therapy information, was included in order to serve the aim of by collecting information on therapeutic goals in aphasia therapy. Therefore, the following specific data were predetermined to be extracted from PWA's case records (Appendix G present the full case record data extraction form).

- Patients' age, gender, ethnicity/nationality, marital status, and educational and occupational status.
- Aphasia onset, severity, type, and characteristics in relation to reading, writing, speaking and comprehension.
- Comorbid medical condition.
- Cognitive abilities.
- Start date of speech and language therapy.
- Number of sessions up until the data collection date.
- Reported goal and objective statements.
- Achieved and unachieved goals, and reasons proposed.
- Statements indicating how goals or sub-goals were set (e.g. patient asked to work on mobile texting).
- Other comments.

2.4 Developing aphasia-friendly materials

Aphasia-friendly materials are defined by four major principles: using simple words and sentences, large sans serif font (e.g. Arial), white spaces, and pictures displaying the main concept (Herbert, Haw, Brown, Gregory, & Brumfitt, 2012; Rose, Worrall, & McKenna, 2003). Studies in the literature have supported the notion that using aphasia-friendly materials assists in the comprehension of PWA (Brennan, Worrall, & McKenna, 2005; Rose, Worrall, Hickson, & Hoffmann, 2011; Rose, Worrall, & McKenna, 2003). Carlsson, Paterson, Scott-Findlay, Ehnfors, and Ehrenberg (2007) argued that strategies should be developed to assist and obtain information from people with difficulties during interviews, rather than excluding them. Thus, to meet the needs of PWA in this current project, information sheet, consent form, and interview questions were adapted in order to assist PWA in comprehending the project and giving their consent to participate, in addition to providing their views in relation to interview questions.

2.4.1 Aphasia-friendly information sheets and consent forms

Information sheets are mainly aimed to provide full detailed information on the project to potential participants in order for them to decide whether or not to participate in the study. When potential participants agree to participate based on the information provided on the information sheets, a consent form is signed in order to protect their rights.

In the current project, information sheets directed to PWA were designed to facilitate their comprehension and aid them in understanding all details about the project in order for them to decide whether or not they agree to participate. Furthermore, consent forms were designed to facilitate PWA’s understanding and ensure that all points in relation to their rights as participants in the study are accessible to them.

To design information sheets and consent forms in an aphasia-friendly format, the “Accessible Information Guidelines” reported by Herbert, Haw, Brown, Gregory, and Brumfitt (2012), as well as recommendations reported by Braunack-Mayer and Hersh (2001), were followed.

The “Accessible Information Guidelines” provide detailed and specific techniques concerning how to design aphasia-friendly materials according to the principles reported in the literature (Brennan, Worrall, & McKenna, 2005; Herbert et al., 2012; Rose et al., 2011; Rose et al., 2003). Therefore, short sentences that contained simple grammar and common words were used. Large Arial font was used in writing the sentences (14–16 pt.). Headings and borders were used to separate messages, and pictures were added in order to support understanding of the messages. Keywords were displayed in bold so as to emphasise important information. Refer to Appendices F and G for the aphasia-friendly information sheet and consent form that were designed for PWA in the current project.

2.4.2 Aphasia-friendly interview materials

Because maximum variation was considered while sampling PWA in the current project (information on maximum variation is reported in chapter 4 under *4.2.2 Sampling*), it was necessary to consider the wide variety of PWA’s skills and needs when designing aphasia-friendly materials for the interviews. A set of aphasia-friendly interview questions were designed based on the interview questions developed following the systematic review, and according to the “Accessible Information Guidelines” (Herbert, Haw, Brown, Gregory, & Brumfitt, 2012). Therefore, each interview question in the set was simplified by using simple words and short sentences. The font used was Arial 14 pt., and keywords were displayed in bold and 16 pt. In addition, borders were used around each interview question so as to draw attention to that specific area.

Meanwhile, other modifications were made in order to simplify each question further by providing answer choices, which was similar to the approach adopted in Noël's (2015) study. Answer choices with regard to communication goals were adopted from two studies that were conducted in a Saudi context of neurological rehabilitation and QoL, which were reported in chapter 1 (Al-Haidary, Qannam, & Lam, 2015; Al Jadaan, 2015). In these studies, the researchers reported communication goals important for individuals receiving neurological rehabilitation (Al-Haidary, Qannam, & Lam, 2015), and communication aspects that are related to QoL of PWA (Al Jadaan, 2015). Examples of answer choices include: “to read”, “to write”, “to find the word you want to say”, “to join a conversation with people”. When answer choices were used, they were presented in Talking Mats™ so as to allow PWA to accept or reject the choices provided. When needed, clear black-and-white drawings were used to clarify messages (*Easternhealth.org.au*, 2017).

Supported conversation techniques (Kagan, 1998) were used during interviews to acknowledge PWA’s responses and reveal their competence. Pen and paper were used to allow for expression through drawing or writing. Furthermore, rating scales from 1 to 5 were used when needed, e.g. when asking about the importance of being involved in goal-setting. Refer to Appendix I for photos that were taken of aphasia-friendly interview materials while conducting the interviews with PWA.

2.5 Chapter summary

In summary, chapter 2 provided information about developing the materials used in this study. Materials development in this study was evidenced based in which interview questions were developed after a systematic review of the literature, while the case record data extraction form and the aphasia-friendly materials were developed based on recommendations reported in the literature.

The conducted systematic review resulted in the development of three interview schedules for the three participant groups (PWA, their family members, and SLTs) that covered questions related to the experience of stroke and aphasia and also goal-setting in aphasia rehabilitation. The designed case record data extraction form was designed to collect demographic information, medical information, and also speech and language therapy information. To assist PWA and facilitate their involvement in this study, aphasia-friendly materials were developed. Information sheet, consent form, and interview questions were designed based on information accessibility recommendations reported in aphasia literature.

The following chapter presents the analysis and translation approaches followed in this study, in addition to the justifications for selecting the reported approaches.

Chapter 3 Selection of analysis and translation methods

3.1 Introduction

This chapter presents the selected analysis and translation methods for the current project. Reflections and justifications for the selected analysis methods are reported at first. Then, cross-language research and translation methods are discussed along with the selected approach to translate data in the current research. The final section of this chapter presents data analysis steps that were taken in this project based on the selected analysis approach.

3.2 Selected analysis methods: Reflections and justifications

In the current project, two analysis methods were used. These methods are as follows:

1- Thematic coding (Flick, 2014).
2- Grounded theory (Glaser & Strauss, 1967; Strauss, 1987).

Adopting the two methods in an overlapping manner allowed condensing and managing the interview data, building thematic structures for participants and groups, analysing case record therapeutic goals data, comparing groups' data (PWA, family members, and SLTs) and interpreting data to highlight core issues. Figure 3.1 presents the analysis methods adopted and their main applications in the current project. Reflections on the methods and justifications for the current project application are presented below.

3.2.1 Reflections on Flick's (2014) thematic coding

Flick's thematic coding was developed to study the differences in perspectives amongst different social groups, in addition to preserving the individuality of cases.

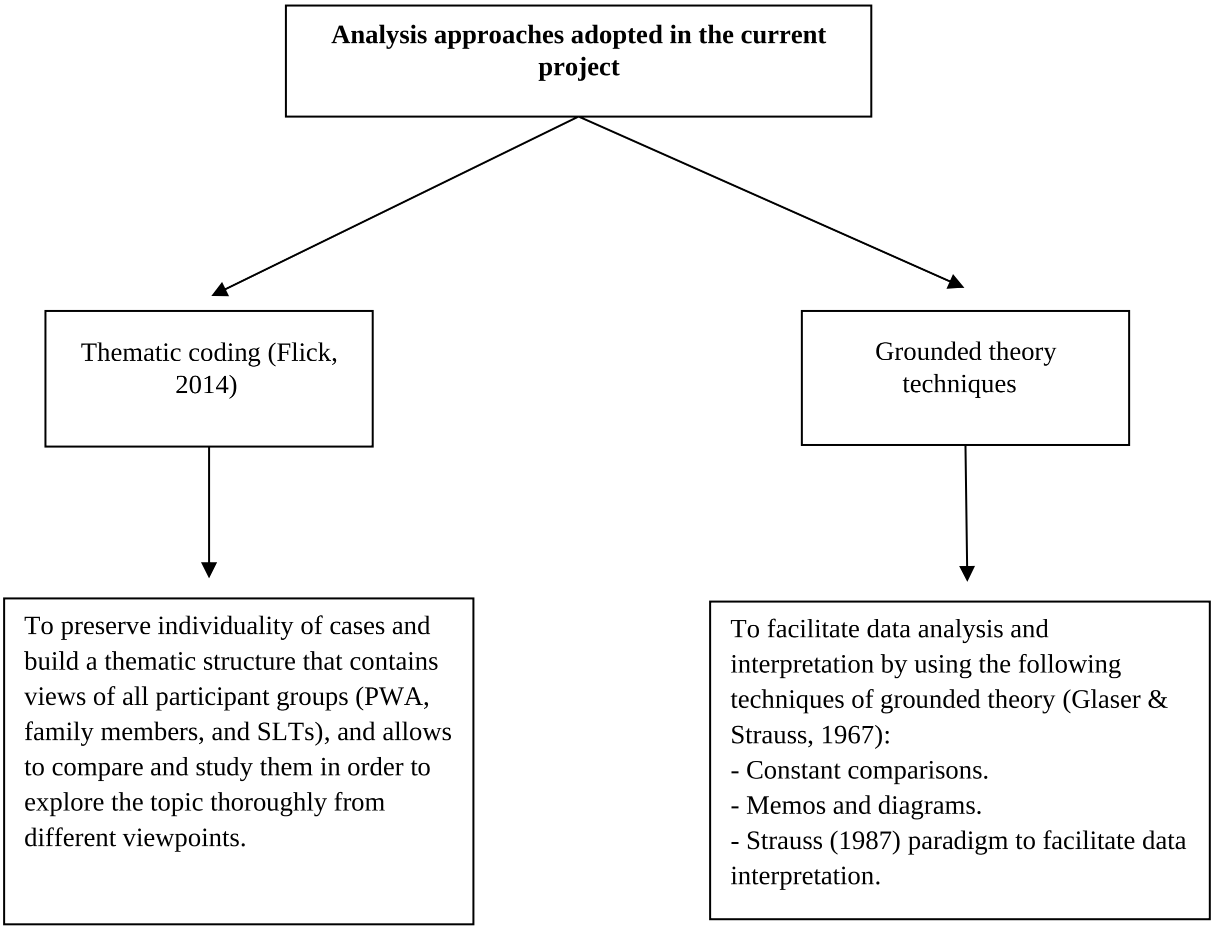


Figure 3.1 Analysis approaches and their applications in the current project

This approach combines methods of thematic analysis and grounded theory in order to code data for comparative purposes. The underpinning theoretical motivation for developing this approach is the heterogeneity of social worlds (Flick, 2014). Flick (2014) argued that the thematic coding approach was developed as a result of some limitations encountered when attempting to apply grounded theory to his study. Flick's (2014) thematic coding approach was designed for comparative studies that involve predetermined participant groups. Since the main aim of thematic coding (Flick, 2014) is to understand the distribution of views on a certain topic, sampling usually is predetermined based on specific group characteristics, and data collection methods are designed in such a way as to collect views on shared topics, unlike grounded theory where the aim is to develop a theory on a topic without predetermining certain aspects.

The process of Flick's (2014) thematic coding includes three major stages. In the first stage, short descriptions of all cases included in the study are developed. In the case descriptions, general information on the participant is presented including age and gender; thereafter, core issues reported are summarised. The next stage of Flick's (2014) thematic coding includes developing a thematic structure. In this stage, open and selective coding are applied to one case in order to develop thematic domains that work as a base for the remainder of the cases. Selective coding in this stage refers to the process of the development of initial themes for a single case, rather than searching for core concepts between all cases (as in grounded theory). Then, the remainder of the cases are analysed and cross-checking of codes and themes is carried out. Comparative dimensions are identified for each case and cross-checked with other cases. For example, how participants viewed the ageing process was a comparative dimension in the study conducted by Flick, Garms-Homolová, and Röhnsch (2012). This cross-checking process allows building a thematic structure that facilitates data interpretation based on the views of different participants. In the later stage of Flick's (2014) thematic coding, data interpretation is completed by further studying of the thematic structure. Flick (2014) suggested the adoption of Strauss (1987) coding paradigm as a framework of interpreting situations present in participants' data. Strauss (1987) coding paradigm consists of four key aspects: the condition of the situation, the interaction amongst individuals, the strategies used to deal with the situation, and the consequences (Flick, 2014). In addition to Strauss' (1987) paradigm, the developed thematic structure is used in interpretation in order to understand the differences and similarities in perspectives amongst participants; hence, conclusions are drawn or data is conceptualised based on the research aims.

The approach holds the advantage of being sensitive to the individuality of cases, in addition to the comparison of overall groups. However, studying cases in depth and conducting comparisons between groups could be time-consuming.

3.2.2 Reflections on grounded theory approach

Grounded theory started as one method developed by Glaser and Strauss (1967) with a specific aim to include inductive theory development based on categories and concepts emerging from data. Details on the method are reported in chapter 1 under *1.7.3.5 Data analysis*. After developing their theory together, Glaser and Strauss took different paths and continued to develop grounded theory according to their different views (Glaser, 1992; Glaser, 2002; Glaser, 1978; Strauss & Corbin, 1997; Strauss, 1987, 1990). An overview of the difference between the Glaserian and the Straussian grounded theory approaches is highlighted by Skeat and Perry (2008). As they reported, the research question and research area are specified in the Straussian approach, whereas the questions and problem emerge from data in Glaserian grounded theory. Thus, the literature is investigated deeply in the Straussian approach, while Glaserian grounded theory considers the literature review to be a step that decreases research objectivity, as it influences the researcher to focus on certain issues. Memos, constant comparisons, and two coding phases (substantive and theoretical) are completed in analysing data in the Glaserian approach. In the Straussian approach to grounded theory, open, axial and selective coding (in addition to memos and diagrams) are used for analysis. Furthermore, the Straussian approach encourages the search for conditions, interaction and consequences while analysing data.

Strauss continued to work on grounded theory with Corbin (Strauss & Corbin, 1997); their work was then criticised by Glaser (1992, 2002). The latter argued that Strauss and Corbin’s method of predetermining the research question, the area of investigation, the literature, and the coding strategies influences data to emerge in a pre-planned way, rather than objectively investigating a phenomenon. Although predetermining the research question, the literature, and the area of investigation seems to direct data in a certain way, as Glaser (1992, 2002) argued, conducting a research project without specifying these aspects is a prolonged, time-consuming process and might be challenging to beginning researchers.

3.2.3 Justifications for adopting selected methods

Selection of the analysis methods is carried out by the researcher based on the project's aim and the type of data collected. The main aim of this project is to explore therapeutic goal-setting within the context of experiencing stroke and aphasia in Saudi Arabia from the views of PWA, their family members, and SLTs. The data collected comprise qualitative data including interview and PWA's case record data. Flick's (2014) thematic coding was chosen to explore and compare the views of participant groups. Meanwhile, grounded theory techniques were chosen to allow for in-depth and iterative analysis of data. Adopting both methods to analyse qualitative data based on the research aims has been reported previously in a study aimed to investigate language and socioeconomic inequality in adolescence (Spencer, 2010).

The purpose of the current research fits the underpinning philosophical standpoint of Flick's (2014) approach. Flick (2014) assumes that perspectives differ among different social groups, and that valuable knowledge could be gained from exploring and comparing groups' opinions on a certain issue. Therefore, applying Flick's (2014) approach was suitable for the purpose of the current research, and allowed reaching the aim of the project by understanding the differences and similarities in the views of different groups of participants. Generating thematic domains at the level of participants, and building a thematic structure for participant groups allowed the researcher to study their views and compare them based on certain issues that emerged from the data. Moreover, Flick's (2014) thematic coding was adopted because PWA vary in their condition and their experience with therapy. Thus, this approach was selected to allow the researcher to study each case in depth by developing a thematic domain for each case and then a thematic structure for all cases together. By doing so, the individuality of cases is preserved and a comprehensive understanding of the issue amongst the social group is achieved. This approach is also systematic in that it has three specific stages, and yet it is flexible because it is iterative and allows for issues to emerge.

Using the grounded theory approach with all key strategies could not be achieved in this project. Theoretical sampling and simultaneous data analysis and collection are key features in grounded theory. These two approaches facilitate data saturation in order to build a theory. In the current project, these techniques were not applied due to time and resource restrictions. Charmaz (2006) reported that the original form of grounded theory developed by Glaser and Strauss (1967) allowed for flexibility and for adopting techniques in research projects when needed. Therefore, techniques from the Straussian grounded theory approach were applied in this project. Constant comparisons and the use of diagrams and memos were also adopted from grounded theory, allowing for constant data review and the documentation of steps through data analysis. Moreover, and as Flick (2014) suggested, Strauss' (1987) paradigm (condition, interaction, strategies and consequences) influenced data interpretation in which guided researcher's thinking of situations present in data and participants' interaction (e.g. rejection of alternative methods of communication and views on masculinity after stroke and aphasia in a more collectivist culture such as Saudi Arabia).

In summary, adopting Flick's (2014) thematic coding and grounded theory techniques complemented one another in this project, allowing to achieve the research aim in combination.

These two methods together allowed to adopt an approach that facilitate preserving the individuality of participants, comparing views, finding core issues, conceptualising data in a systematic way, as will be discussed in detail in this chapter.

3.3 Cross-language research and translation

Cross-language research is a type of research that involves more than one language, e.g. data being collected from participants who speak Arabic and then a bilingual researcher disseminating data in English as in the current project. In cross-language research, translation of collected data is an essential step that should be considered and planned before data analysis. As Al-Amer, Ramjan, Glew, Darwish, and Salamonson (2016), and Temple and Young (2004) confirmed, the literature shows a lack of explicit reporting on translation processes, and on how data in the source language (SL) was translated into the target language (TL) in cross-language research. The literature reveals that there is no standardised procedure for the translation of collected data in cross-language studies. However, the majority of researchers agree on using the method that will maximise the validity of translation based on the research nature and the researcher's point of view. Factors that influence translation in cross-language research and an overview of the methods suggested in the literature are reported below.

3.3.1 Factors influence translation in cross-language research

The quality of translation is influenced by factors that can directly impact on the resulting validity of the data. These factors can be managed in order to ensure validity. These factors include the translator's competence, using back translation, and the timing of translation.

The translator's competence should be taken into consideration in respect of both languages (Chen & Boore, 2010; Santos Jr, Black, & Sandelowski, 2015). Moreover, the translator's knowledge of both cultures should also be considered in order to ensure that meanings are conveyed rather than literal word-by-word translations provided (Al-Amer et al., 2016; Chen & Boore, 2010).

The use of back translation is another factor that could affect the quality of translation since this method is used to ensure the reliability of translation. In this method, a transcript is translated from the source language to the target language, and then again to the source language. Thereafter, the first and final versions are evaluated in relation to each other (Chen & Boore, 2010). Following this process, the researcher performs a quality check with regard to the accuracy of meanings and the first translation step (from source language to target language). However, back translation by itself, and regardless of other considerations, cannot ensure the quality of translation, as it has been argued that there is no one single exact translation of a transcript (Temple & Young, 2004).

Translation timing is a factor that should be considered in cross-language research. Researchers have argued about the timing of transforming the source language into the target language. Santos Jr, Black, and Sandelowski (2015) stated that translation timing in cross-language research has been reported in the literature in five forms. Researchers could translate the source language into the target language prior to data collection (e.g. translating data collection instruments), during data collection (e.g. simultaneous interpretation during interviews), during data preparation (e.g. verbatim transcriptions), during analysis (e.g. categories and concepts), and upon dissemination (e.g. research report).

3.3.2 Overview of translation methods reported in cross-language research

Chen and Boore (2010) reported in their review of cross-cultural research that adequate translation requires full translation of the original data, blind back translation (where the back translator does not access the original document), repeating the previous two steps until translation is acceptable, and another translator reviewing the target language version. The researchers reported that this approach is expensive financially and time-wise. They proposed another method that could save time and money and, at the same time, increase translation validity. The researchers suggested that analysis be conducted in the source language and then two translators translate categories and concepts. Thereafter, back translation is completed by another translator; finally, a panel committee judge the overall translation process by comparing the source language with target language.

Santos Jr, Black, and Sandelowski (2015) addressed the issue of translation timing by examining two cross-language studies that were translated at different phases. In their research, the translation process occurred late in the first study, as the final report was translated from Portuguese to English. In the second study, translation occurred at an early stage in which interview transcripts were translated from Portuguese to English before analysis commenced. The researchers found that both translation timing and the translator's competence, in addition to the object of translation (e.g. transcripts, themes or the final report), should be considered and reported in cross-language research. Furthermore, the researchers recommended adopting the method of early translation of data because it allows researchers who are included in the study but do not speak both languages (target language and source language) to interact with all of the data collected. For researchers who use later translation timing and those who are proficient only in the target language, Santos Jr, Black, and Sandelowski (2015) suggested discussions surrounding data analysis with bilingual co-researchers in order to minimise the impact of a lack of access to all datasets.

Al-Amer, Ramjan, Glew, Darwish, and Salamonson (2016) discussed the challenges in translating data from source language Arabic to target language English in medical research, and outlined some recommendations for maximising the integrity of translation in qualitative research. In their research, 15 Arabic-speaking participants with diabetes were interviewed with respect to their views on self-care management behaviours. Thereafter, all interview data was translated into English and analysed using the thematic analysis approach. The researchers discussed the challenges encountered while translating data including preserving the meaning between the source language and the target language and the translation of metaphors and medical terms. They recommended that researchers who are involved in cross-language research to be close to their data and record some observations and feelings during interviews they conduct with participants in their projects. For analysis, they recommended that it is more convenient to be completed in source language Arabic so as to preserve the meaning, with translation occurring later at the levels of themes and categories. Finally, they stated that it is important for all cross-language researchers to report their method when translating the source language into the target language, and to take into consideration the dialect and the aim of translation in order to maximise reliability and preserve the meaning of the Arabic cultural context.

In summary, the literature does not provide a standardised procedure for data translation in cross-language research. Although there is no systematic procedure of translation upon which researchers have agreed, some researchers provided recommendation to translate data in qualitative cross-language research. Ensuring the competence of the translator and their cultural knowledge, performing back translation and taking into consideration the timing of the translation process, and late-stage translation in order to preserve meaning and cultural aspects are reported recommendations in the literature.

3.3.3 Selected translation approach and justification

As reported previously, the literature does not provide a systematic or standardised translation procedure for cross-language research. In the current project, preserving the meaning in data and ensuring the reliability of translation were the two priorities taken into consideration when choosing the translation method. Figure 3.2 presents the overall translation method utilised in the current project.

PWA's case record had already been documented in English by SLTs in charge of PWA's cases; thus, no translation was needed after data was collected. Arabic interview transcripts were coded in the original language so as to ensure that the Arabic cultural context and meanings were preserved. When all codes for each single case were completed, the translation process began. To ensure reliability in the translation process, a reliability check, back translation, and a discussion were carried out. Following are the translation steps taken in order:[1]

1- The original Arabic codes were all translated from Arabic to English by the main researcher. The product of this process was called "English codes version 1".

2- The original Arabic codes were all translated from Arabic to English by the first bilingual translator who speaks Arabic and English. The product of this process was called "English codes version 2".

3- The two English versions were compared and discrepancies were identified by the main researcher.

---

[1] Translation reliability checks were completed by a professional agency for translation services, and were self-funded by the main researcher.

4- "English codes version 1" was translated back into Arabic by the second bilingual translator who speaks Arabic and English. The product of this process was called "Arabic codes version 1".

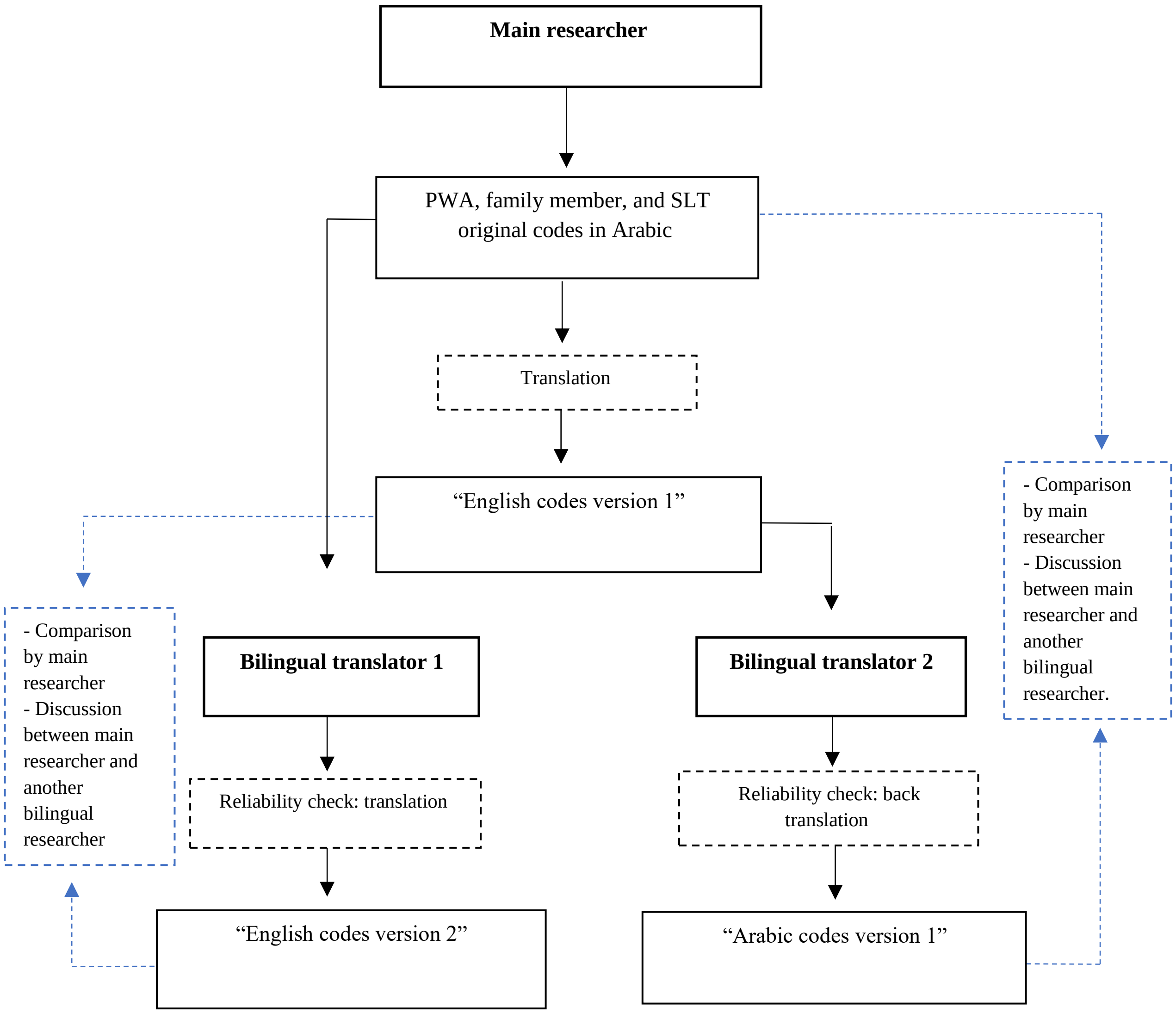


Figure 3.2 The translation approach followed in the current project

5- The original Arabic codes and "Arabic codes version 1" were compared and discrepancies were identified by the main researcher.

6- Discrepancies between the compared versions were discussed by the main researcher and another bilingual researcher in the field of aphasia. Modifications were made when needed in order to ensure that Arabic meanings were reflected in the English translation.

In summary, the translation method selected in this research was chosen to ensure two important aspects: preserving the meaning of texts in the original language and ensuring the reliability of translation. The steps followed in translating the data were based on recommendations reported in the literature on cross-language research.

3.4 Data analysis

This section of chapter 3 provides a detailed presentation of data management and interpretation steps that were taken in the current project using the selected analysis methods as reported previously. This section is divided into two main subsections: data management steps and data interpretation. Figure 3.3 presents an overview of the data management and analysis process, which is discussed in detail below. In Figure 3.3, processes in green numbered boxes are elaborated in other figures or supported by examples in tables; below is the box number and the related table or figure in this chapter:

-Box 1: Examples of the coding process are provided in Table 3.1.

-Box 2: The process of translation and its reliability is illustrated in Figure 3.2.

-Box 3: The process of building one comprehensive thematic structure is illustrated in Figure 3.4.

3.4.1 Data management

Data management included a set of steps that were taken to condense, categorise and prepare the data for interpretation.

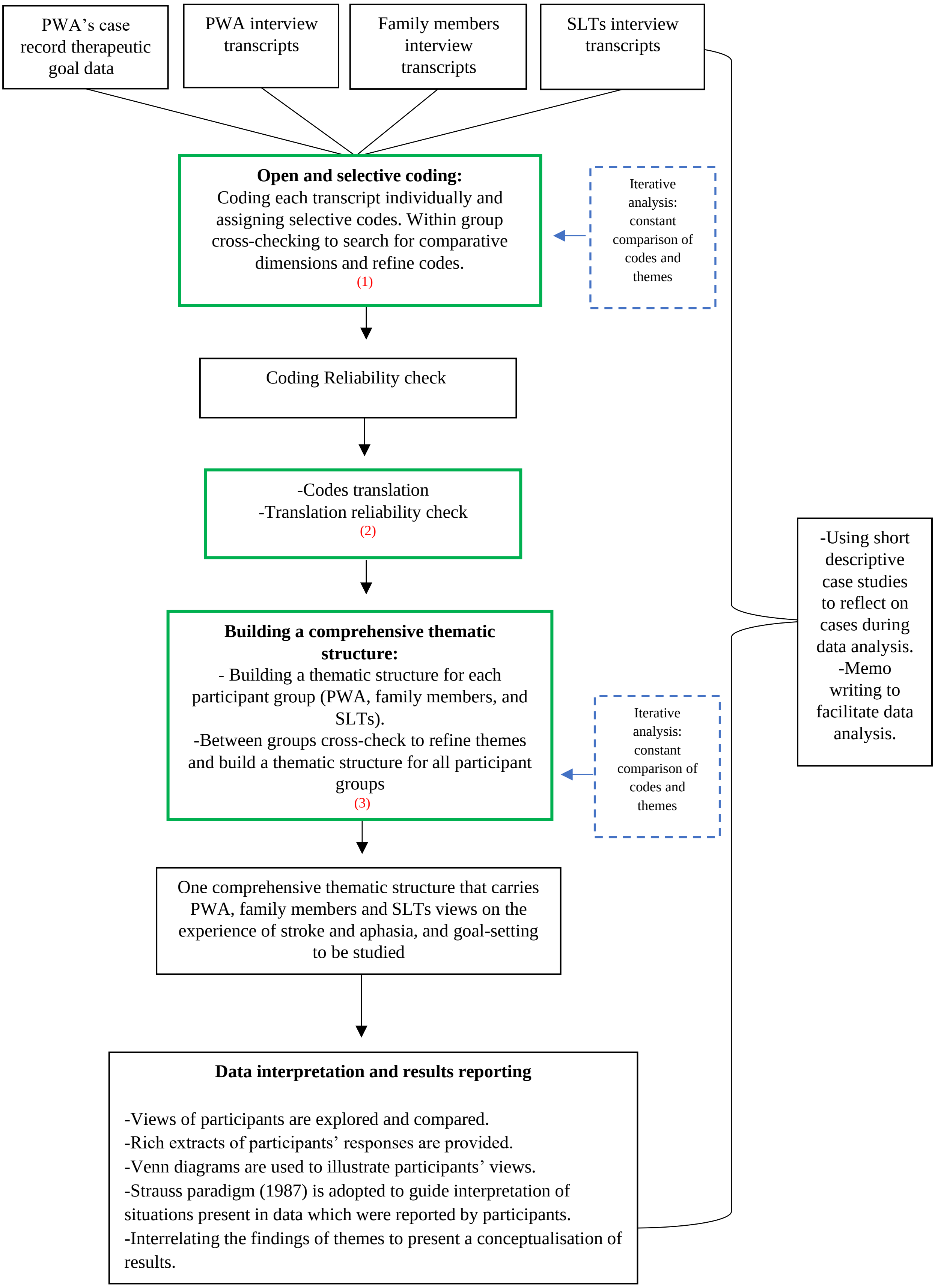


Figure 3.3 An overview of the data management and interpretation process

These steps consisted of transcribing interviews, case description and memos writing, data coding (sub-codes, open codes, selective codes), and the development of themes in the comprehensive thematic structure.

3.4.1.1 Transcribing

All participants were audio-recorded during interviews for the purpose of transcribing interviews in order to prepare data for analysis. Details on audio recording are provided in chapter 4 under *4.4.5 Audio and video recording*. Participant interviews were transcribed verbatim within dialects by researcher. Transcribing interviews verbatim within dialects was decided upon because data collection was undertaken in Saudi Arabia and a variety of dialects are found amongst the population there. In addition, verbatim transcription was conducted because a group of participants were PWA and it was necessary to report their full utterances so as to achieve a reliable interpretation and analysis of their words. Nonverbal communication was identified in transcripts with squared brackets (see Humble, 2015; McLellan, MacQueen, & Neidig, 2003). The following are examples of nonverbal communication that was transcribed for participants in the current study: [cry], [laugh] and [pause]. Words or phrases that were unintelligible or inaudible were identified in the transcription as follows: [inaudible segment]. Private and identifiable information including the names of other people and places, that was provided by participants during interviews was not transcribed for confidentiality purposes. Instead of transcribing the names of people mentioned or places, a blank line was added (Humble, 2015; McLellan et al., 2003). After all interviews had been transcribed, transcripts were reviewed by listening to the audio recordings to check accuracy in order to ensure rigour (Poland, 1995).

3.4.1.2 Short description of cases

Following the approach of thematic coding (Flick, 2014), short descriptions of cases were developed. Firstly, a "motto", which is a phrase that reflects a participant's core concern or belief, is stated. Then, descriptive information of participants is provided. The descriptive information is extracted from PWA's record and from the short background questionnaires that family members and SLTs completed. For PWA, aphasia characteristics, age, gender, and educational and occupational status are reported. Meanwhile, for family members, age, gender, and educational and occupational status are reported. Finally, for SLTs, age, gender, and educational status, in addition to experience and areas of interest, are reported. In the third section of the case descriptions, a short summary of each participant's experience with stroke and aphasia and general view of goal-setting is reported. Below is an example of a written case record for patient 009p.

"I did not want; I did not want anything except wellness."

> *009p is a 57-year-old Saudi male. 009p is married, has children and used to work in an industrial company in Saudi Arabia. He had a right hemiparesis haemorrhagic stroke in 2016. Informal assessment revealed that 009p has verbal expression difficulty and word-finding problems in conversation and connected speech. 009p experienced a sudden stroke occurrence in a social gathering. His communication difficulties affected his social participation. 009p received inpatient and outpatient rehabilitation services in Riyadh. He worked with the SLT on improving expressive skills in connected speech according to case record notes. 009p thinks that the participation of PWA alongside SLTs in setting aphasia*

therapeutic goals is hindered by PWA's inability to express and share. Therefore, he handed such responsibility to SLTs, as he reported in the interview.

3.4.1.3 Memos

For the purpose of the current study, writing memos allowed the researcher to document and store data related to the analysis and interpretation. Memos were documented in the form of short paragraphs, diagrams, and bullet-point notes. Memos in the current project were documented for the following purposes:

- Analysis plan in points and diagrams.
- Translation steps.
- Analysis and translation rigour.
- Coding steps and notes on codes and themes.
- Notes on how codes and themes were refined through the constant comparison technique.
- Notes on core issues emerging during interpretation and how they relate to one another.

3.4.1.4 Thematic coding according to Flick's (2014) approach

The following sub-sections provide information on the thematic coding process undertaken in this study. At first, an overview of the coding process is presented. Then, detailed information on the process of building individual thematic domains and a comprehensive thematic structure are provided.

3.4.1.4.1 Overview of the coding process

All interview transcripts were imported to ATLAS.ti, which is qualitative data analysis software that helps to manage and retrieve codes and quotations. Firstly, open coding was undertaken for one transcript that belongs to a participant with aphasia. Then, selective coding was conducted in order to build thematic domains for said participant. In this project, and as Flick (2014) reported in his method, selective coding refers to the process of building initial thematic domains for single cases. The same process of building thematic domains was carried out for one family member's and one SLT's interview transcripts. The process of building initial thematic domains for the first three cases is reported in detail in Chapter 5 under "Pilot study II".

The next step concerned completing coding separately for the remainder of the transcripts in each participant group, as well as cross-checking within groups. Thus, transcripts of PWA were coded; then, all PWA data were cross-checked. Each transcript of family members was coded and cross-checked as well. The same process was conducted for SLTs, wherein each transcript was coded; then, all data were cross-checked. This step is consistent with Flick's (2014) approach, as it allows for a deep single-case analysis before comparing the views of participants together.

The final step comprised cross-checking themes between groups in order to build a comprehensive thematic structure that facilitated comparisons of participants' views. By doing so, case individualities are preserved, yet data is organised and presented in one comprehensive thematic structure. Figure 3.4 below illustrates how themes of the comprehensive thematic structure were developed from the open codes of all participant groups.

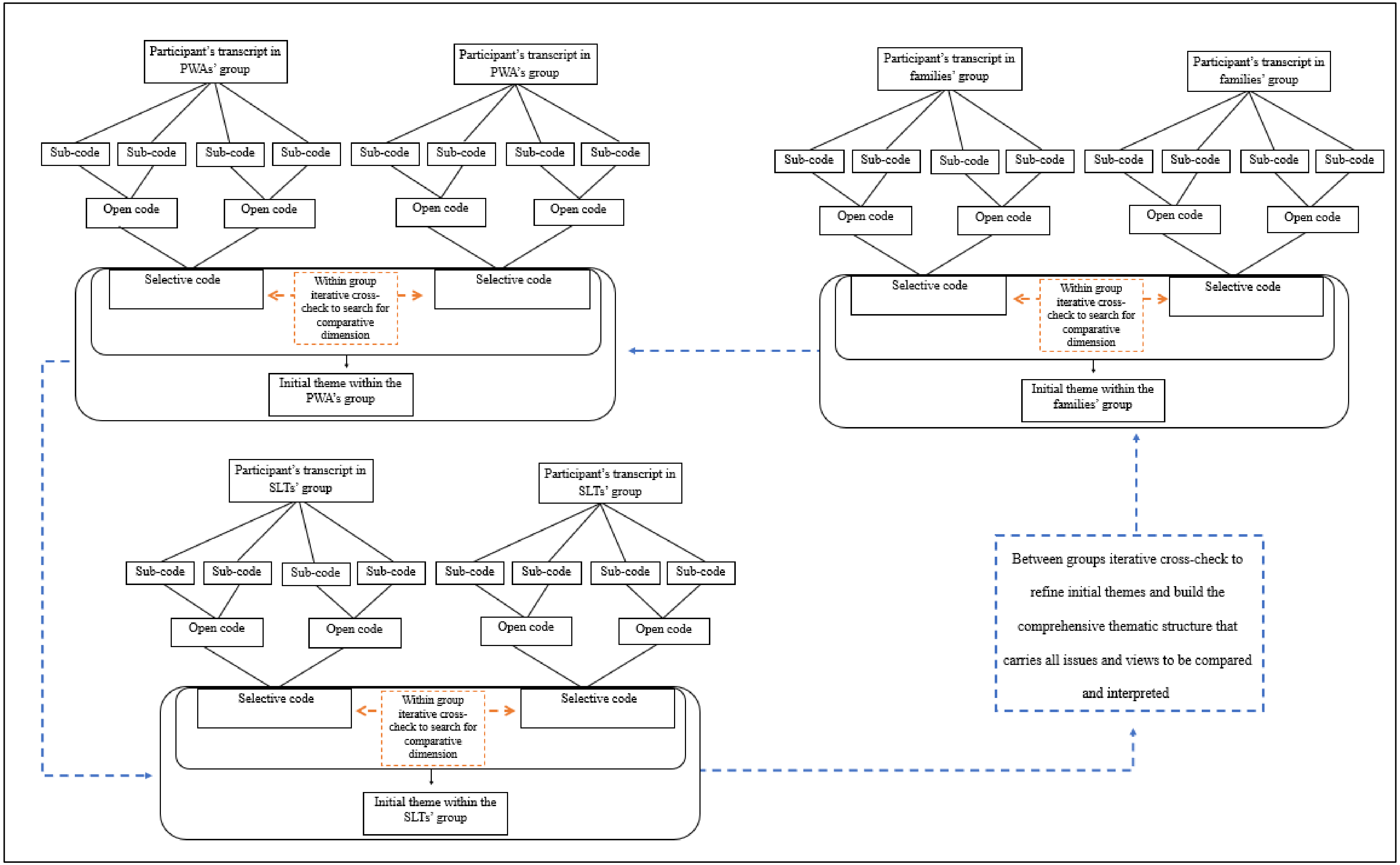


Figure 3.4 The iterative process of building themes in the comprehensive thematic structure

Figure 3.4 presents two sample cases in each participant group in order to illustrate the process. This process is described in detail below in the following two sub-sections.

3.4.1.4.2 Open and selective coding

In the process of open coding, each interview transcript was read several times by the main researcher and then assigned open codes in ATLAS.ti.

Open codes were descriptive, using short phrases or nouns that best reflected the participants' own views towards the discussed topic (e.g. need for family support, not important to participate in goal-setting).

For data management purposes, and because of the large amount of data presented in ATLAS.ti, a second phase of open coding was completed. This step was taken when a single code in ATLAS.ti carried many sub-codes; however, it was challenging to manage the large number of codes and code groups in ATLAS.ti. ATLAS.ti allows exporting a codebook for each transcript that includes all codes and quotations related to the transcript. Thus, for each transcript in ATLAS.ti, an Excel codebook was exported for further sub-categorical coding when needed. Table 3.1 presents an example of the coding process, including open and selective coding, in addition to initial themes and memos that facilitated later data interpretation.

Open codes were read, reread and studied within the context of each interview individually for selective coding. Comparative dimensions were searched for and the relationships between open codes were examined so as to build higher categories and assign selective codes. Views related to the experience of stroke and aphasia, and goal-setting were explored and grouped (e.g. matched and unmatched expectations, changes in family dynamics).

Table 3.1 An example of the coding process relating to one theme in the comprehensive thematic structure

Participants	Interview extracts	Sub-codes (Excel coding)	Open codes (ATLAS.ti coding)	Selective codes (potential competitive dimensions)	Initial theme within the participant group	Memos
Participant with aphasia	HA: Did you help the specialist in choosing therapy goals? 0024p: Yes, I did. HA: Like what? 0024p: I told her I could not read the Quran or to think about it my mind, like an illiterate person who cannot read. This is what has happened in my brain; I cannot read or even speak. HA: You suggested the Quran to her so that you practice reading and become better. 0024p: Yes.	-Participating in choosing therapeutic goals -Reciting Quran is a goal	Sharing personal goals	The extent of participation in goal-setting	Participation in goal-setting.	0024 expressed that she shared her concerns with the SLT that she cannot read the Quran as she used to, and that she wants to work in therapy on that area. This reflects the importance of such religious activity goals among people since Islam is the predominant religion in Saudi Arabia.
Family member	HA: Did you participate with the SLT in choosing therapy goals? Did you suggest anything for example? 0030f: No. she knows, to be honest we don't know what are the means to achieve. I do whatever they ask me to, I don't know. HA: The steps you take to achieve. 0030f: Yes, for example, like cardiologists, we don't know what to do, we do what they instruct, but we don't know.	-Non- participation -Trust in SLTs' knowledge as health care professional	Trusting SLTs as decision makers	The extent of participation in goal-setting	Participation in goal-setting	The participant did not view her participation in goal-setting as important. She preferred following the SLT's plan (a qualified person) to avoid mistakes and to make sure that the means suggested by the SLT leads to the final goals.

SLT	0016s: Emmm, she was Emmm, on the opposite, I mean his wife did not interfere, she was feeling that this is my job, so she did not try to interfere except in the cases where it was right to do. I mean for example, if he did not get cueing form me, or different dialect. For example, if I give him a name of something in a different dialect, she corrects me or tell him in their dialect, that she means that, so he understands her, so she was helping me in this way, but I always go back and ask her, was his answer right? For example, when I ask him, how many children do you have? How many daughters do you have? These questions when he answers them, she was helping me with the answers without making the patient aware that she was assisting me.	-Non- participation of family members. -Trust in SLTs' knowledge as health care professional. -Assisting SLT in dialectal differences.	Trusting SLTs as decision makers	The extent of participation in goal-setting.	Participation in goal-setting	The SLT expressed that the wife of the person with aphasia did not interfere in relation to what the SLT's therapeutic goals for her husband because she trusted the SLT. The wife provides her input in therapy session in relation to activity items and her husband's responses. Some PWA and their families might feel appreciated to be involved in discussions related to therapeutic goals, and some share their personal goals that reflect their values. PWA and their families might prefer decisions about therapeutic goals to be made by the SLT. PWA and families might have high trust in SLTs as the main decision makers in relation to therapeutic goals. They view SLTs as health care professionals who know the best means to reach the desired goals.

Views on factors, facilitators, barriers and consequences were all considered when attempting to find connections between open codes so that they could be clustered. Within-group cross-checks were completed in an iterative manner to refine selective codes (e.g. the extent of participation in goal-setting).

3.4.1.4.3 Building a comprehensive thematic structure

As an initial step and for each participant group (PWA, family members, and SLTs), a thematic structure was built to aid visualisation and data organisation. These were undertaken as a pre-step before building the comprehensive thematic structure for all participant groups together. Thus, for each participant group (PWA, family members, and SLTs), open and selective codes of participants were studied, and selective codes were combined into higher level of initial themes that best represented the issue in order to be cross-checked between groups. For example, both “Sudden life changes” and “Knowledge of stroke and aphasia among society” were grouped under the initial major theme of “Stroke occurrence and the social context”.

Between-group crosschecks were conducted in an iterative manner to refine initial themes and build one comprehensive structure. This process resulted in developing one comprehensive thematic structure that holds major themes (initial themes), sub-themes (selective codes) and views of all participants (open codes). The complete comprehensive thematic structure is presented and interpreted in chapter 6 (Results). This process is illustrated above in Figure 3.4.

In relation to the comprehensive thematic structure, some themes emerged from only one participant group’s data including “Identifying therapeutic goals”, which appeared in the data of SLTs, leaving it as a unique view of SLTs. Other themes held dyadic views of PWA and their family members, including “Stroke occurrence and the social context”, whereas the rest of themes held triadic views of PWA, their family members, and SLTs.

3.4.1.5 Constant comparisons

Quotes of participants' responses were read and reread by the researcher in order to re-examine the relationship between quotes and assigned codes and ensure that codes represented quotes. By applying the technique of constant comparison, codes were added, renamed, split, collapsed or merged (when needed) by the researcher to refine them and build categories that best represented the codes.

The relationships between code groups and themes were also examined through all phases of data analysis. As with codes, themes were renamed, split or merged to be refined and to reach the final version that represented all participants' views. The process of examining open codes, groups and themes is cyclical. Thus, the examination process was completed in an iterative manner at the level of building individual thematic domains for participants until the level of building a comprehensive thematic structure for all groups together (PWA, family members, and SLTs).

3.4.1.6 Strategies to ensure trustworthiness of findings

Research rigour and enhancing trustworthiness in qualitative research were discussed in detail in chapter 1 (Literature review) in section *1.6.4 Research rigour*. In the current project, different strategies were adopted in order to enhance trustworthiness, as suggested in the literature. Following are the strategies used in this project:

- Analysis was documented in detailed steps to ensure consistency. Analysis steps were supported by examples and diagrams to ensure transparency of the procedure.
- Justifications were provided to the reader to ensure transparency of the decision-making process.

- Transcripts were reviewed by listening to the audio recording before the coding process to check accuracy and amend if needed in order to ensure credibility.
- Adopting a translation approach that includes different appropriate skilled translators performing reliability checks and back translation to ensure rigour of the translation process.
- An intercoder reliability check to ensure rigour of the coding process. Details of the intercoder reliability check are reported under *4.5.2 Analysis rigour* in chapter 4 (Research methods).
- Triangulation of data sources evident in analysing and incorporating PWA's case record goals with goals reported in interviews by participants.
- Triangulation in the study design evident by capturing three different views (PWA, their family members, and SLTs) on the same topic (the experience of stroke and aphasia, and goal-setting) to increase the depth of understanding.
- Rich extracts of participants' responses were provided to ensure transparency and allow the reader to make judgments about themes and their representation of participants' views.
- Transferability of results to another context was considered as detailed information on the methods and participants was provided to give the reader the chance to examine applicability to other contexts.

3.4.2 Data interpretation

Results interpretation facilitated the conceptualisation of goal-setting within the context of experiencing stroke and aphasia in Saudi Arabia.

The developed comprehensive thematic structure, which encompasses all issues and views that emerged from participant groups (PWA, family members, and SLTs), is the main framework for data interpretation. Moreover, Strauss (1987) paradigm was adopted to guide the analysis and interpretation of situations occurring in data and expressed by participants.

By using the thematic structure for data interpretation, participants' views (which were grouped under themes) were discussed, and visualised using Venn diagrams. In the interpretation and thinking process, the condition, interaction, strategies and consequences were searched for, as Flick (2014) recommended adopting Strauss (1987) paradigm. For example, in the theme "Stroke occurrence and the social context", a person with aphasia expressed *"You are a man, how did you let the water fall from your hand…"*. The participant's reaction and dealing with his physical weakness while experiencing stroke symptoms suggested that views on masculinity in Saudi society (a collectivist society) could be influenced by the vulnerability that PWA experience because of stroke.

Chapter 6 (Results) provides the complete comprehensive thematic structure. Rich extraction of participants' responses is provided in order to support the discussions. In addition, Venn diagrams are used to report the views of participants and compare and discuss them. Chapter 7 (Discussion and conclusion) presents discussions of results in relation to the research context and other context reported in the literature. Chapter 7 also presents a conceptualisation of findings in the Saudi context.

3.5 Chapter summary

In summary, this chapter provided detailed information on the data analysis and translation methods followed in the current project. Analysis in this project followed two methods reported in the literature with respect to managing and interpreting data. The two analysis methods are

Flick’s (2014) thematic coding and grounded theory (Glaser & Strauss, 1967; Strauss, 1987). These methods allowed the researcher to reach the aim of the study, which is concerned with exploring goal-setting within the context of experiencing stroke and aphasia. The translation approach was selected based on recommendations reported in the literature which emphasised preserving meaning in the source language and ensuring the reliability of translation. The justifications for selecting the analysis and translation methods (in addition to the steps taken) are reported above in detail and supported by diagrams. The results of data analysis are reported in chapter 6 (Results).

Chapter 4 Research methods

4.1 Introduction

This chapter provides an overview of participant sampling, recruitment and characteristics. Then, this chapter presents the study design, followed by an overview of data collection materials, context, and procedure. In the final section of this chapter, an overview of data analysis and research rigour is provided.

4.2 Participants

The total number of participants in this study was 29. Since it has been reported in the literature that the number of participants in the majority of qualitative interview studies is around 15 ± 10, which might change due to factors including time and resources (Kvale, 2007), 29 was considered an appropriate and sufficient number for the current study. This number was also believed to appropriate in order to achieve the stated aim of investigating the views of the three groups of participants within a time limit and ensure adequate depth in the views collected was identified through analysis.

4.2.1 Participant groups

Participants included 11 people with aphasia (PWA), 11 family members which included one family member without aphasia for each individual with aphasia, and the speech and language therapist who provided speech and language therapy for the PWA. Some SLTs managed more than one of the cases, and hence only seven SLTs were recruited. These SLTs completed all of the data collection procedure for each case separately.

4.2.2 Sampling

Sampling in this research aimed to include triads engaged in aphasia therapy, where each triad consists of a participant with aphasia, a family member and the SLT in charge of the case. The aim behind this triadic sampling was to gather the views of different parties with different roles, albeit involved in the same experience of aphasia therapy in order to collect rich accounts. Therefore, the same experience is exposed from different angles in order to explore the topic in depth and enhance the trustworthiness of findings.

Sampling for the specific group of PWA was purposive. This was decided so as to achieve maximum variation in the research sample, as well as ensuring that the sample was as representative as possible to the population of PWA. In that way, research trustworthiness can be maximised, and the transferability of findings is enhanced because the sample is highly representative of the population. Four factors were determined to be linked to the variation in the selected sample; these include:

1- Age.
2- Gender.
3- Educational and occupational status.
4- Aphasia characteristics (severity, type, onset, and rehabilitation service (be it inpatient or outpatient).

Regarding family members and SLTs, the need to include triads in the study as described above meant that recruitment of the other two members of each triad was determined by the PWA. Therefore, family members who wanted to take part and the SLTs involved in providing aphasia therapy to selected PWA were recruited.

4.2.3 Inclusion and exclusion criteria

Since the participants in this study consisted of PWA, family members, and SLTs, inclusion and exclusion criteria differed according to the group. The inclusion and exclusion criteria for each group are reported below.

4.2.3.1 PWA

PWA were considered eligible to participate in the study if they met the following criteria:

1. Arabic speakers.
2. Aged 18 or above.
3. Diagnosed with aphasia post-stroke by an SLT.
4. Were at least two months post-stroke at the time of the study.
5. In a stable medical condition.
6. Have adequate cognitive abilities and sufficient comprehension abilities to participate in interviews, as judged by the SLT from assessment information and interaction, and by the researcher from screening.
7. Being able to communicate their thoughts through the use of supporting materials in a brief screening interview conducted by the researcher.
8. Currently receiving inpatient or outpatient speech and language therapy at the participating sites.
9. Absence of a history of other neurological or psychiatric illness.
10. Having normal premorbid language skills and literacy level.
11. Able to give informed consent to participate in the study.

PWA were excluded from the study if they had a severe cognitive deficit or comorbid condition (unintelligibility of speech, hearing impairment, or visual impairment) which restricted their abilities to participate in interviews and use the aphasia-friendly supporting materials. Furthermore, PWA were excluded if they were unable to communicate their thoughts through the use of supporting materials in all three screening interview questions.

4.2.3.2 Family members

Family members were eligible to participate in this study if they met the following criteria:

1. Arabic speakers.
2. Aged 18 or above.
3. Related to the person with aphasia.
4. In a stable medical condition.
5. Absence of a history of other neurological or psychiatric illness.
6. Having normal language skills and literacy level.
7. Have adequate cognitive, visual and hearing abilities to participate in interviews.
8. PWA expressed willingness to participate in the study with the named family member.
9. Family member gave informed consent to participate.

Family members were excluded from the study if they did not meet the inclusion criteria or did not have an interest in participating in the study.

4.2.3.3 SLTs

SLTs were eligible to participate in this study if they met the following criteria:

1. Arabic speakers.
2. Licensed by the Saudi Commission for Health Specialties.
3. Providing or have provided therapy to one of the participants with aphasia participating in the study.

SLTs were excluded from the study if they did not meet the inclusion criteria or did not have an interest in participating in the study.

4.2.4 Ethics, recruitment and consent

4.2.4.1 Ethical approval

Ethics application forms were completed and submitted for review to the ethics application system at the University of Sheffield. Applications were reviewed by the university ethics reviewers, and approval was granted by the Department of Human Communication Sciences Research Ethics Committee at the University of Sheffield to conduct the study on 30/4/2018.

Once approval was granted by the University of Sheffield to conduct the study applications for ethical approval were submitted to King Fahad Medical City and Sultan Bin Abdulaziz Humanitarian City in Riyadh in order to enable the recruitment of participants. Ethical approval was obtained from King Fahad Medical City on 23/5/2018 as a letter was signed and sent by the chairman of the institutional review board. Ethical approval was also obtained from Sultan Bin Abdulaziz Humanitarian City on 1/7/2018, with a letter being signed and sent by the chairperson of the research and ethics committee. All ethical approval letters obtained from the three institutions are included in Appendix J.

4.2.4.2 Recruitment

Both research sites are located in Riyadh, Saudi Arabia. Sultan Bin Abdulaziz Humanitarian City is a non-profit medical rehabilitation hospital established by Sultan Bin Abdulaziz Al Saud Foundation. It provides medical services for children and adults according to international standards. Sultan Bin Abdulaziz Humanitarian Medical City provides different inpatient rehabilitation programmes including spinal cord injury, stroke and cardiac rehabilitation (Sultan Bin Abdulaziz Humanitarian City, 2019).

King Fahad Medical City is one of the advanced establishments of the Saudi Ministry of Health. The medical city consists of four different hospitals and medical centres that specialise in different areas and provide inpatient and outpatient services. The four hospitals in King Fahad Medical City comprise the main hospital, the children specialised hospital, the women specialised hospital and the rehabilitation hospital (King Fahad Medical City, n.d.).

The three participant groups in this study (PWA, family members, and SLTs) were recruited from both Sultan Bin Abdulaziz Humanitarian City and King Fahad Medical City in Riyadh, Saudi Arabia. SLTs were identified through supervising SLTs in both sites, while PWA and their families were identified through the SLTs recruited.

After obtaining site approval to conduct the study, the researcher contacted the supervising SLTs at the respective departments of speech and language therapy at both medical cities to visit and discuss the project in person. During the visits, the researcher explained the research project and provided both SLTs with information sheets describing the project in detail and containing the researcher’s contact information. The researcher answered all enquiries asked by the supervising SLTs during the visits.

The recruitment of SLTs was facilitated by supervising SLTs, as agreed between them and the researcher. Supervising SLTs contacted SLTs in their department and provided them with the research information sheets. SLTs were encouraged by the supervising SLTs to participate in the study if their case load contained aphasia cases, and were encouraged to contact the researcher via the email address or mobile number provided on the information sheet if they had questions regarding the study. Some SLTs who agreed to participate contacted the researcher directly, while others informed the supervising SLTs about their agreement. The researcher met the SLTs who agreed to participate, answered their questions, and provided and explained the consent form.

SLTs who agreed to participate signed the consent forms.

To recruit PWA a list of the inclusion and exclusion criteria previously mentioned was submitted to recruited SLTs at both participating sites. Based on the criteria submitted, SLTs were able to identify a number of eligible participants for the study. PWA who met the inclusion criteria were contacted by the SLT in charge of their case with regard to the study. SLTs also approached their family members who attended therapy sessions with them, explained the research and asked if they were willing to participate in the study. This method allowed both PWA and their family members to have time to think about participation, and to discuss the study between themselves to reach a shared decision of whether to participate or not. This method saved time and enhanced the chances of triad recruitment involvement. When PWA and their family members verbally agreed to participate and informed their SLTs about their decision, SLTs contacted the researcher to arrange to meet them and explain the study. The researcher met PWA and their families who agreed to participate, answered their questions, and provided them with information sheets. PWA were provided with aphasia-friendly information sheets (Appendix H shows the developed aphasia-friendly information sheet). Some PWA and their family members agreed to participate in the same meeting; thus, consent forms were provided, explained and signed during the meeting (Appendix H shows the developed aphasia-friendly consent form). Meanwhile, others asked to think about participating in the study, in which case another meeting was arranged in order to provide, explain and sign consent forms with PWA and their family members.

4.2.4.3 Informed consent

As mentioned in the previous section, participants who verbally agreed to participate were given consent forms to sign. Consent forms were collected from participants prior to data collection.

To minimise coercion, participants were informed that there were no obligations to agree with participating in this study, and that they had the right to withdraw at any time after participation without justification. PWA were assured that their refusal to participate in this study would not affect their therapy sessions received at the sites by any means. In addition, SLTs and family members were assured that their views and all information that they provided would not be used to judge or evaluate their knowledge and skills.

All participants were assured that their identities would be kept anonymous and that their names would be encoded. Furthermore, they were informed that members of the research team, including the researcher and two supervisors, could access the recordings and transcripts. All participants were informed that they could agree to or disagree with the use of audio and video data in conferences and presentations, as well as the storage and further analysis of data following completion of the project.

To maximise the possibility that all participants with aphasia would give informed consent, information sheets and consent forms were designed in an aphasia-accessible format (Appendix H shows the developed aphasia-friendly consent form). In addition, information on the study was provided to the family members who attended the sessions with PWA, and they were encouraged to read the information forms, discuss them with the PWA and ask questions to the researcher.

The researcher supported each person with aphasia in completing the consent form, with their family member being present. The researcher read the consent form document aloud with the participants with aphasia. Each point within the document was checked with the PWA before signing. PWA who signed the consent forms and agreed to undergo screening in the same session were screened for interviewing eligibility.

4.2.5 Participant characteristics

In the following sub-sections, participant groups' characteristics are presented. Regarding SLTs, specific characteristics of each participant are not detailed in order to ensure confidentiality of participants since there is a possibility to identify them, and also identify their responses in the results chapter.

4.2.5.1 PWA

PWA who participated in this research were five females and six males *(n = 11).* All participants with aphasia were native to Saudi Arabia except for one participant who was from a nearby Arabic country but lived in Riyadh. Seven participants lived in Riyadh and received aphasia rehabilitation services there, while four participants were originally from the western region but had to travel to Riyadh to receive rehabilitation services. Seven participants were receiving outpatient aphasia rehabilitation services, while four were receiving inpatient services. Participants' ages ranged between 24 and 68. A distribution of participants' age and gender is presented below in Figure 4.1 showing that most participants' age ranged between 45-66.

All participants in the current study had acquired brain injury, which had resulted in aphasia in most cases. One participant (003p) presented with cognitive linguistic deficits as described by the SLT in charge of the case. The SLT in charge of 003p's case documented in the record that 003p was alert, semi-cooperative throughout the assessment, and aware of his expressive language difficulties. The SLT also reported that based on the informal assessment, 003p presented with difficulties in answering yes/no questions, following commands, producing automatic speech, repetition, naming, and sentence formation. Because of the presence of aphasia symptoms, a decision to include 003p in the study was made by the researcher.

PWA who participated in the study varied in their marital status, as eight were married, two were single, and one was divorced. Moreover, PWA varied in their educational and occupational status. Five PWA hold a high school degree, two hold a Bachelor's degree, and four PWA's educational status was not reported in their records. Five PWA were not working, four were retired, one male stopped working after stroke, and one female participant continued working after the occurrence of stroke. All PWA were living with their families and were taken care of by family members.

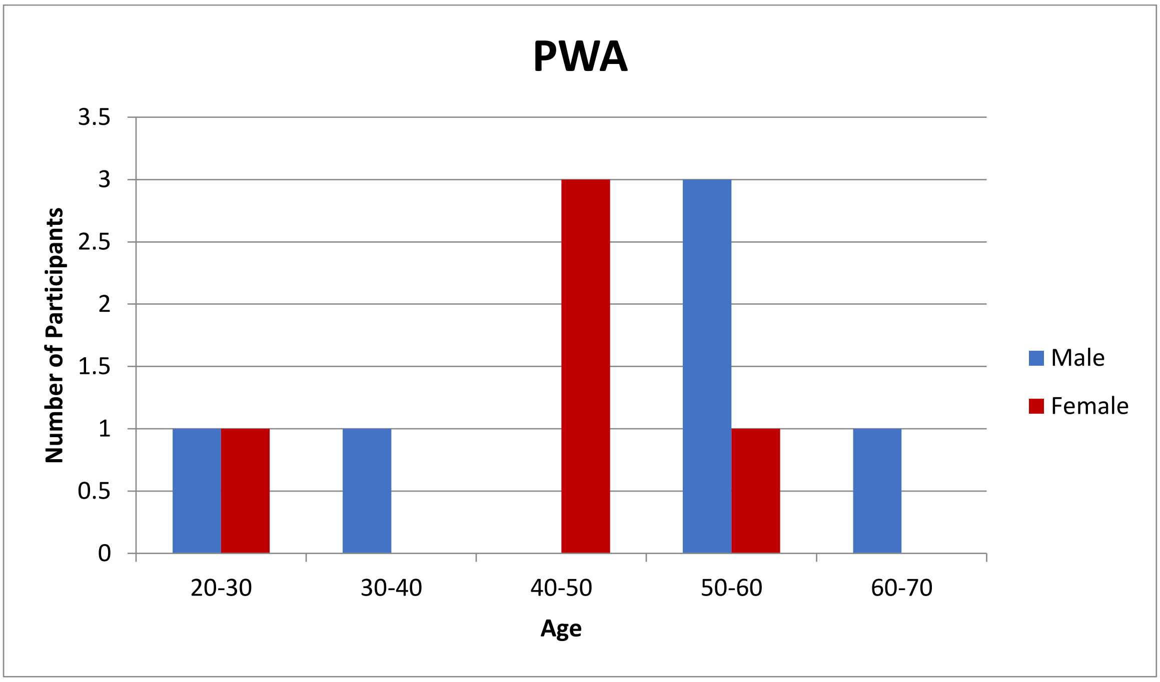


Figure 4.1 PWA's age and gender

Table 4.1 presents information related to PWA who participated in the current study, including: stroke and aphasia characteristics, family member who participated, and which SLT provided aphasia therapy and participated in the relevant triad.

Table 4.1 PWA's information

PWA	Age	Gender	City of living	Marital status	Educational/ occupational status	Stroke onset and type	Service	Aphasia characteristics/SLT's impression	Family member	SLTs
003p	68	Male	Riyadh	Married	High school /retired	4/6/2018 Right MCA stroke	Inpatient	Moderate cognitive linguistic deficits	Son 004f	005s
006p	28	Female	Riyadh	Single	High school /not working	16/3/2017 Left MCA stroke	Outpatient	Non-fluent aphasia	Mother 007f	008s
009p	57	Male	Western region	Married	Not reported/ retired	28/03/2016 Haemorrhagic stroke in right hemiparesis	Outpatient	Verbal expression difficulties and word-finding problems in conversation and connected speech	Son 0010f	0015s
0011p	24	Male	Western region	Single	High school /not working	24/20/2017 Left hemisphere stroke following a car accident	Inpatient	Expressive aphasia	Father 0012f	0016s
0013p	58	Male	Western region	Married	Not reported / retired	23/6/2018 Acute CVA	Inpatient	Fair auditory comprehension and severe expressive language problems	Wife 0014f	0016s
0017p	41	Female	Western region	Married	Bachelor's degree /working	July 2016	Outpatient	Non-fluent aphasia	Husband	005s

						MCA and left internal carotid artery occlusion			0018f	
0019p	38	Male	Riyadh	Married	Not reported/stopped working after stroke	1/2017 CVA, temporoparietal and occipital infarction	Inpatient	Good comprehension and anomia	Wife 0020f	0021s
0022p	48	Female	Riyadh	Married	High school /not working	September 2016 Left MCA stroke	Outpatient	Non-fluent aphasia	Daughter 0023f	005s
0024p	54	Female	Riyadh	Separated	High school /not working	10/03/2017 Stroke following liposuction	Outpatient	Non-fluent aphasia	Daughter 0025f	0026s
0027p	49	Female	Riyadh	Married	Not reported/not working	Last stroke was a left MCA in May 2015 as a result of Moyamoya disease	Outpatient	Non-fluent aphasia	Husband 0028f	0026s
0029p	59	Male	Riyadh	Married	Bachelor’s degree / retired	19/2/2018 Left frontoparietal intracerebral haemorrhage	Outpatient	Non-fluent aphasia	Wife 0030f	0031s

MCA = Middle cerebral artery
CVA = Cerebrovascular accident

By looking at PWA’s characteristics presented in this paragraph, Figures 4.2, and Table 4.1, variation in the sample in relation to the four factors reported in section *4.2.2 Sampling* can be observed. Therefore, maximum variation using purposive sampling was achieved.

In this study, all information related to the aphasia profile of participants with aphasia was collected from PWA’s case records. In PWA’s case records, aphasia descriptions were not standardised because of the absence of standardised tests in Arabic, which justifies the non-standardised descriptions in Table 4.1. Formal aphasia standardised testing materials are not available in Saudi Arabia. Therefore, SLTs adopt informal tests that are known to be used in each facility. These informal testing materials allow testing areas that are targeted in standardised testing, including: spontaneous speech, auditory comprehension, verbal expression, and repetition. This informal assessment method allows SLTs to capture areas of strength and weakness, thus reporting general impressions (e.g. fluent or non-fluent aphasia) and specific characteristics of the aphasia profile. This method of informal assessment does not provide a picture of PWA’s performance in comparison to normative data, but it does allow SLTs to compare PWA’s abilities prior to therapy to their abilities post-therapy. This informal testing is conducted upon admission, be it inpatient or outpatient, or when there is a long gap between outpatient sessions.

4.2.5.2 Family members

Family members who participated in this study were five males and six females *(n = 11)*. All family members were native to Saudi Arabia except for one who was from a nearby Arabic country. Family members’ ages ranged between 22 and 65. Figure 4.2 below presents family members gender and age distribution.

Figure 4.2 shows that family members' age is distributed equally between two age ranges (22,44 and 44,66); however, it should be taken into consideration that one participant did not report age which leaves one participant's data missing from this Figure.

Similar to PWA, four family members were from the western region, while seven were from Riyadh. Four family members hold a Bachelor's degree, three hold a high school degree, two hold a middle school degree, one holds a PhD degree, and one reported that she does not hold an educational degree.

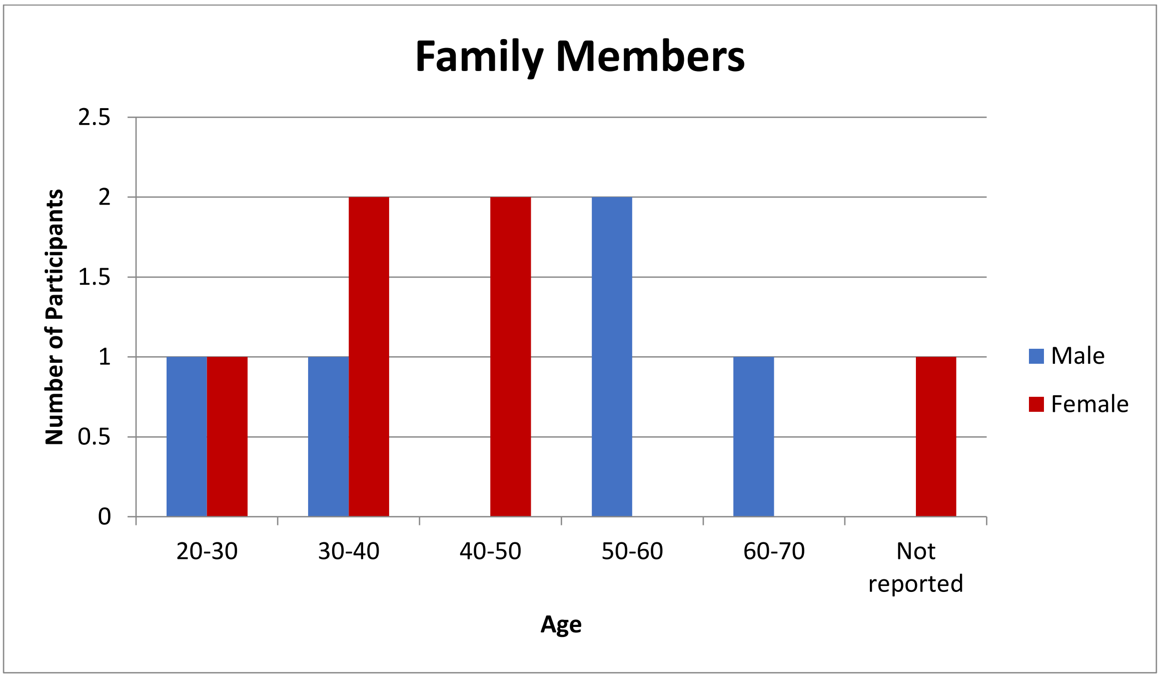


Figure 4.2 Family members' age and gender

The majority of family members included in this study did not work (six), whereas three reported working and two reported that they have retired. In six triads, the relationship between PWA and family members was a parent-child relationship, while in the remaining five triads family members were spouses of PWA being either a wife or husband of a person with aphasia.

Table 4.1 shows PWA and family members relationships, and Table 4.2 shows information related to family members who participated in the current study.

Table 4.2 Table 4.2: Family members' information

Family member	Relationship to PWA	City of living	Gender	Age	Educational status	Occupational status
004f	Son of 003p	Riyadh	Male	36	PhD	Working
007f	Mother of 006p	Riyadh	Female	45	None	Not working
0010f	Son of 009p	Western region	Male	22	High school	Working
0012f	Father of 0011p	Western region	Male	58	High school	Retired
0014f	Wife of 0013p	Western region	Female	Not reported	Middle school	Not working
0018f	Husband of 0017p	Western region	Male	50	Bachelor's degree	Working
0020f	Wife of 0019p	Riyadh	Female	31	Middle school	Not working
0023f	Daughter of 0022p	Riyadh	Female	28	Bachelor's degree	Not working
0025f	Daughter of 0024p	Riyadh	Female	38	Bachelor's degree	Not working
0028f	Husband of 0027p	Riyadh	Male	65	Bachelor's degree	Retired
0030f	Wife of 0029p	Riyadh	Female	49	High school	Not working

4.2.5.3 SLTs

Because of the small number of SLTs included in this study, the demographic information of each individual was not reported in detail. Such detailed presentation of information could lead to identifying SLTs and also identify their responses in the results section, hence compromising data confidentiality in the current study.

SLTs participated in the study and all were native to Saudi Arabia except for one who was from another Arabic speaking country. Six of the SLTs were females and one was a male (*n=7*). Their ages ranged from 24 to 44, and they possessed clinical experience ranging between one and eight years. All SLTs hold a Bachelor's degree in speech and language therapy except for one who holds a Master's degree. All SLTs were licensed to practise as SLTs by the Saudi Commission for Health Specialties. Four SLTs worked in and were recruited from King Fahad Medical City, while three worked in and were recruited from Sultan Bin Abdulaziz Humanitarian City. Figure 4.3 presents SLT's age and gender.

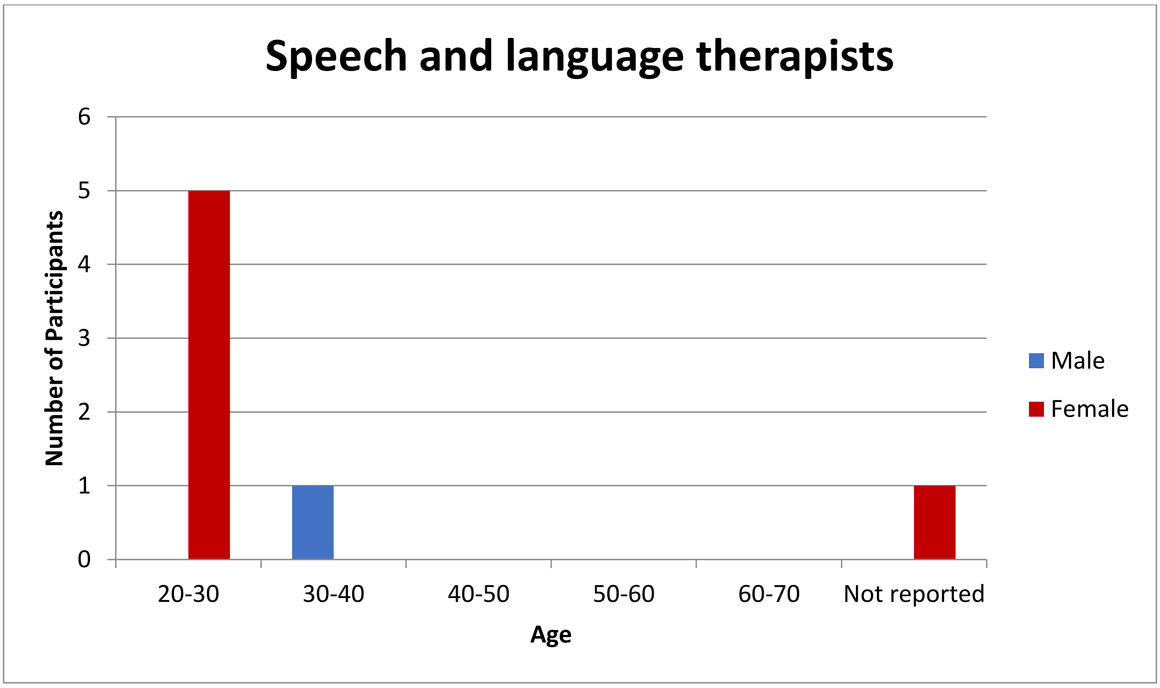


Figure 4.3 SLT's age and gender

4.3 Research design

In the current research, a qualitative research methodology was selected as the most appropriate approach in achieving the research aims. The study involves three participant groups - PWA, family members, and their SLTs – and two sets of data, namely in-depth semi-structured interviews and PWA's case record information.

The study design involved literature review, developing materials, obtaining ethical approval, piloting developed data collection materials, data collection, piloting data analysis approach, and data analysis which are shown in Figure 4.4.

The literature in the area of aphasia therapeutic goals and goal-setting was extensively reviewed, as reported in detail in chapter 1 (Literature review). By identifying two areas that have not been explored before in the Saudi Arabia, this study aimed to explore goal-setting for aphasia within the Saudi context of the stroke and aphasia experience. Novel materials were developed, ethical approval was obtained to conduct the study, and a pilot study was conducted to test interview questions, aphasia-friendly materials, and case record data extraction form.

Then, data was collected from three participant groups in two medical cities in Saudi Arabia, and qualitative analysis methods were piloted and used to analyse interview and case record data. Pilot studies are reported in detail in the follwoing chapter 5. Themes were identified form participants' data and discussed, and a conceptualisation of goal-setting within the context of stroke and aphasia experience was presented in chapter 7 (Discussion and conclusion) by interrelating the findings of themes.

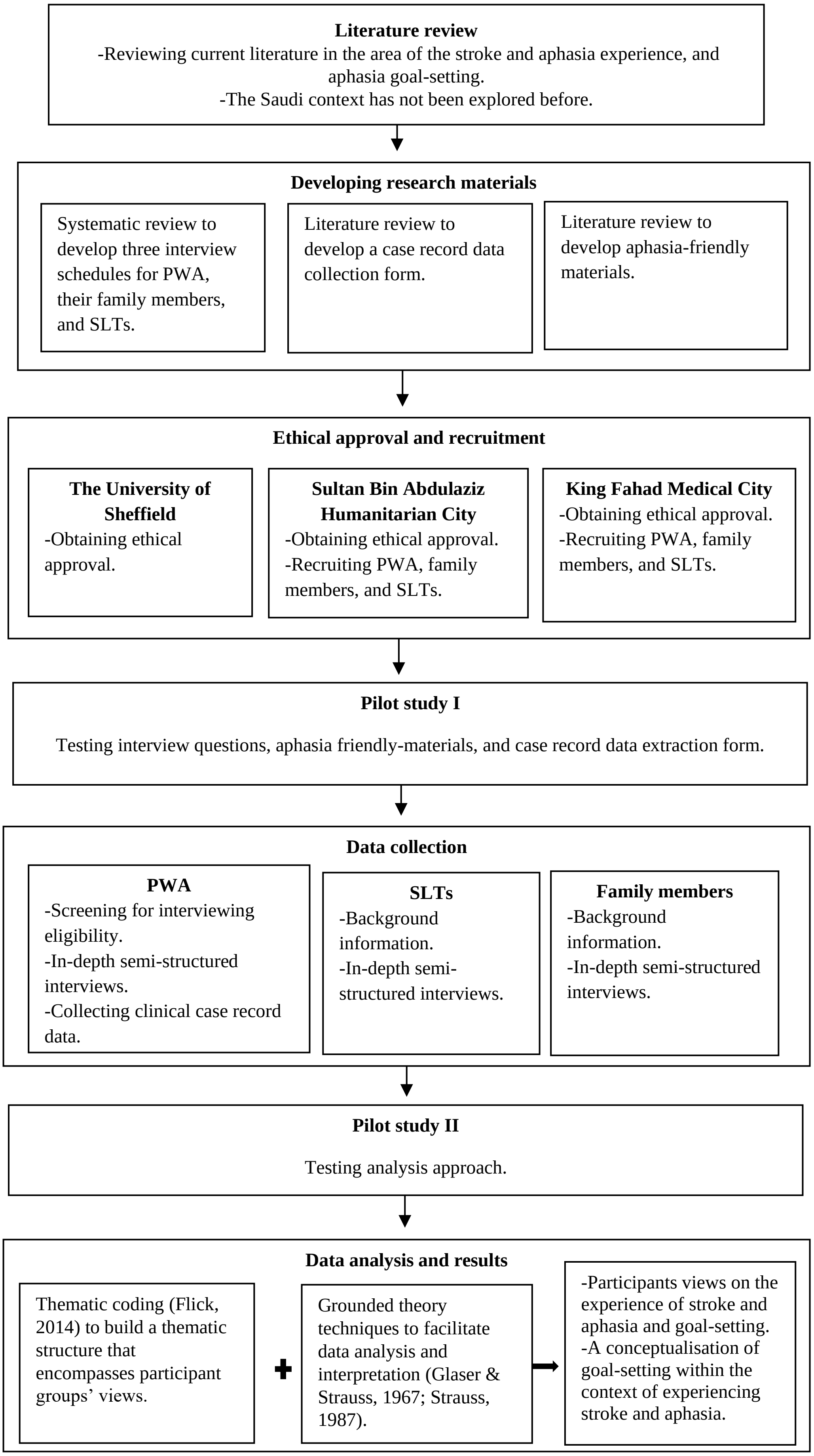


Figure 4.4 An overview of research design

4.4 Data collection

4.4.1 Data collection context

The data collection was undertaken in the two participating settings, namely King Fahad Medical City and Sultan Bin Abdulaziz Humanitarian City, in Riyadh.

In King Fahad Medical City, data collection took place in the department of speech and language therapy in the rehabilitation hospital. The department offers inpatient and outpatient speech and language therapy sessions. Inpatient stroke survivors receive intense aphasia rehabilitation services, as they have a certain daily schedule for different rehabilitation therapy that they require, including physiotherapy and occupational therapy. Outpatient speech and language therapy services are arranged between SLTs, PWA and their families and scheduled according to needs (as judged by SLTs) and the availability of slots.

In Sultan Bin Abdulaziz Humanitarian City data collection was undertaken in the stroke unit, where the staff also provide inpatient and outpatient speech and language rehabilitation services for stroke survivors. Similar to King Fahad Medical City, inpatient services are provided on a daily basis for PWA, while outpatient services are arranged and scheduled between SLTs and PWA according to therapy plan.

In both medical cities some stroke survivors apply for inpatient services because they come from different cities that do not provide rehabilitation services and hence require accommodation. They prefer inpatient services because they are scheduled, intensive, and provided within the hospital in which they are staying. Their eligibility to receive inpatient rehabilitation services is judged by the rehabilitation physician who decides upon the severity of the case, the prognosis, and the type of rehabilitation therapy needed. An overview of participants' recruitment and the data collection procedure is presented in Figure 4.5.

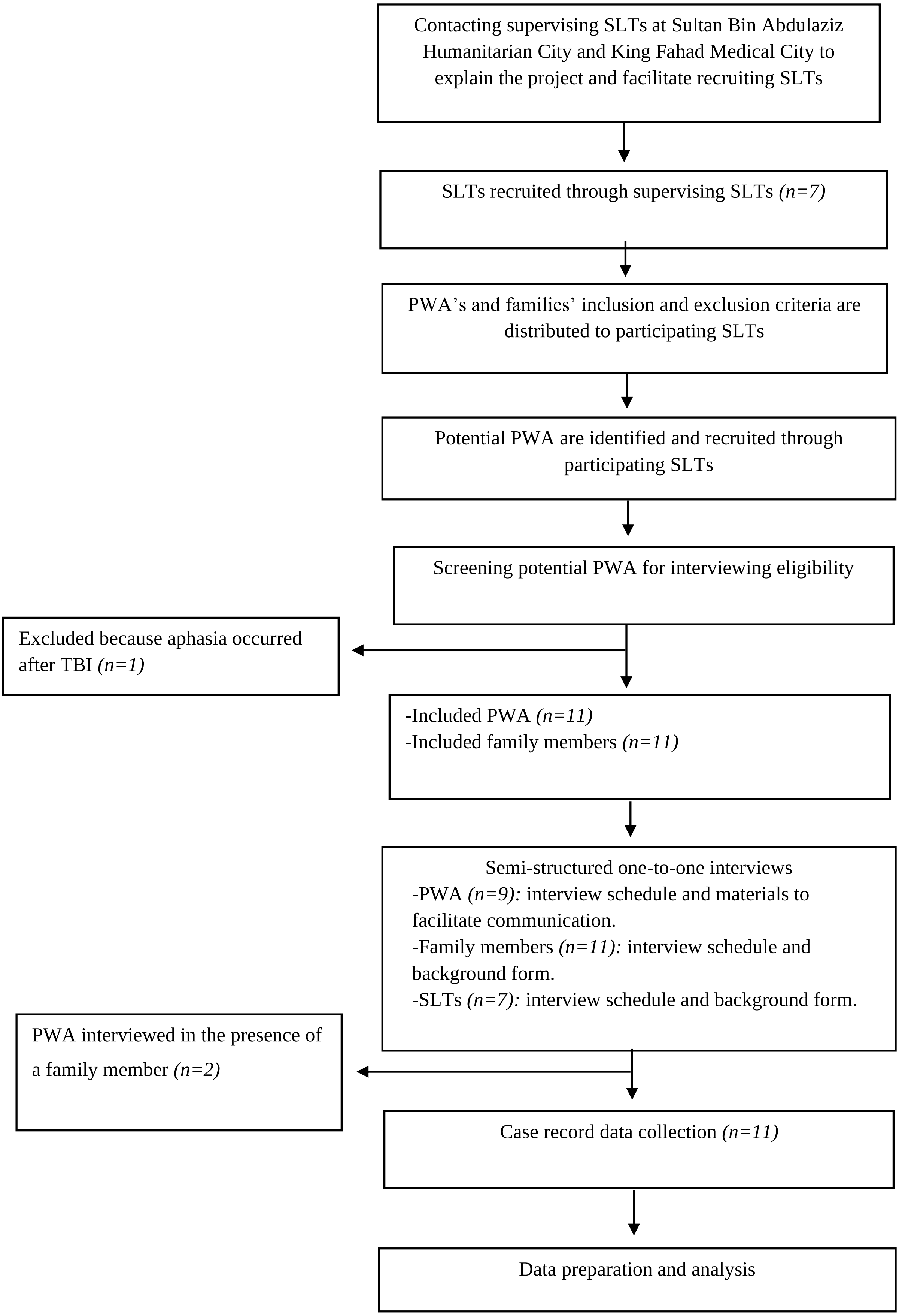


Figure 4.5 Overview of recruitment and data collection procedure

4.4.2 Data collection materials

Data were collected by conducting in-depth semi-structured interviews with PWA, family members, and SLTs, as well as extracting data from the clinical case records of PWA. Data collection materials is described in detail in chapter 2 (Development of research materials).

Three interview schedules were developed for the three participant groups after a systematic review of the literature. A data extraction form to collect information form PWA' records was also developed following recommendations reported in the literature. Moreover, aphasia-friendly consent form and information sheet in addition to aphasia-friendly interviewing materials to facilitate the communication of PWA during interviews were developed based on recommendations reported in the literature.

Background forms were developed to collect information from family members and SLTs. There was no background form designed for PWA, as their information was collected from their case records using the data extraction form mentioned previously. These background forms aimed to collect data related to participants' characteristics.

Families' forms included demographic information, referral questions, and two open-ended questions about PWA's condition and how family members communicate with PWA in order to grasp a background picture of the cases. SLTs' background forms included demographic information and questions about their clinical experience.

4.4.3 Interviewing participants

4.4.3.1 Screening PWA

Upon the first meeting with potential participants, comprehension was assessed by conducting a brief interview as a trial for entry. The aim of this brief interview was to determine whether participants with aphasia were able to communicate their thoughts, as well as ensuring that the included participants with aphasia possessed sufficient comprehension and expressive abilities to participate in an in-depth semi-structured interview. Screening also aimed to ensure that PWA's visual and physical abilities did not impose any restrictions upon them in using Talking Mats^{TM}. Screening prior to interviews in order to test participants' eligibility to communicate using aphasia-friendly materials has been reported in the literature (Beringer, Tönsing, & Bornman, 2013; Harty, Griesel, & Van der Merwe, 2011; Pettit, Tönsing, & Dada, 2016).

PWA were informed on the information sheet that they would undertake a brief interview in the screening phase, and that they may or may not be invited to participate in the study after screening. The screening day was scheduled between SLTs, PWA, their families and the researcher, and was mainly during scheduled speech and therapy session time. Screening was undertaken in a quiet clinical therapy room, and lasted between 15 and 20 minutes depending on the responses of PWA. All screening sessions were audio-recorded. PWA who passed the screening were given the choice of undertaking the main interview on the same day or scheduling it for another day. This step was undertaken based on SLTs' suggestions so as to ensure interviewing inpatients before being discharged, as well as interviewing outpatients before their next session, which might be far apart.

The screening session started by welcoming PWA and giving them the choice of being screened individually, with a family member present, or with SLTs. Then, they were informed about the screening procedure and that they would be asked three general questions about their lives. They were encouraged to use the aphasia-friendly materials to support their communication during the interview. The researcher ensured confidentiality and informed PWA that if they had feelings of tiredness or fatigue, they would be offered a rest, or interviews could be stopped and rescheduled. Then, audio recorders were turned on and screening commenced.

The materials used in the screening phase included Talking Mats^{TM}, supported conversation techniques (SAC) (Kagan, 1998), and three screening questions, as follows:

1. Tell me about your life before aphasia.

   Prompt: Did you work? If yes, what did you do?

2. Tell me about your family.

   Prompt 1: Do you have kids? If yes, how many?

   Prompt 2: Do you have brothers and sisters? If yes, how many?

3. What activities do you enjoy doing?

Questions were presented in Talking Mats^{TM} and were read aloud by the researcher. Options in respect of answers were also presented to PWA to select from when they faced difficulties in expressing or conveying their thoughts. PWA had to answer all three questions, whether using supporting materials or not, in order to be included in the study.

In the current study, all potential participants who were recruited through SLTs were able to pass the screening examination except for one participant, who was excluded because he had aphasia post-traumatic brain injury hence did not meet criteria for inclusion, and did not pass the screening assessment showing a severe expression difficulty. The high number of PWA who passed the screening examination could be attributed to the SLTs' judgment of PWA who have adequate comprehension skills and can undertake interviews, as these were criteria reported in the list distributed to SLTs. Therefore, the number of screened PWA was 12, while the number of participants included in the study was 11.

4.4.3.2 Interviewing procedure

Interviews with PWA, family members, and SLTs were conducted in Sultan Bin Abdulaziz Humanitarian City and King Fahad Medical City in quiet clinical therapy rooms. Interview dates and times were arranged between the researcher, SLTs, PWA, and their families according to their speech and language therapy session schedules and their availability to participate in interviews. For inpatients, SLTs arranged with the PWAs and their families to meet the researcher during their speech and language therapy session or at another time between rehabilitation sessions. For outpatients, SLTs arranged for the interviews to be conducted within the speech and language therapy session time slots with the verbal consent of participants. For the SLTs, the researcher arranged a suitable time to meet with them to conduct their interviews.

Interviews were conducted in Arabic as it is the first language of all participants. English phrases and terminology were used by some participants to express thoughts or medical issues. Interviews varied in duration among the participants. The average interview duration was 24 minutes. The longest interview lasted for 1 hour and 10 minutes and was conducted with a participant who had aphasia while the shortest interview lasted for 11 minutes and 54 seconds and was conducted with an SLT.

For all participants, interview sessions started by welcoming and thanking participants for their interest in participating in the research. Participants' confidentiality was ensured and they were informed that they could stop to take a break if they wished to do so. Thereafter, the researcher followed the interview schedule by asking the questions aloud to participants. Questions were asked in the same sequence presented in the interview schedules provided in chapter 2 (Development of research materials). Questions were asked in a simple, everyday Arabic dialect in order to ensure accurate comprehension. The researcher also probed so as to elicit answers and thoughts when needed. At the end of the interviews, the researcher thanked the participants for their valued responses and time and allowed for further questions or queries.

During or immediately after interviews, the researcher collected subjective field note information that included information on participants' mood, emotional expressions (crying), and openness to share information. This information was used to enhance the researcher's understanding of participants' experience and status.

4.4.3.3 Variations in interviewing PWA

All participants' interviews followed the same procedure. However, some variations were taken into consideration when interviewing PWA due to the nature of their communication difficulties.

Family members and SLTs were asked to complete the background forms prior to their interviews. The researcher asked family members and SLTs to fill in the form and assisted them if they had difficulties in answering the questions. As mentioned previously, PWA were not given such background forms, as their information was collected from their clinical case records.

It was pre-planned to conduct all interviews individually, and that if PWA preferred their family members to be present in their interviews, the family members would be interviewed prior to the person with aphasia in order to ensure that the views that they reported were their own. However, all PWA in the current research agreed to undertake their interviews individually, but two family members decided to attend the interviews with their relatives with aphasia. The husband (0028f) of a participant with aphasia attended the interview session with his wife, and the daughter (0025f) of a participant with aphasia preferred to attend her mother's interview after the interview had started. The researcher asked family members politely to minimise their input, as the aim was to extract the views of PWA.

PWA's interviews were supported by the use of Talking Mats^{TM} and supported conversation techniques. Each question was presented in an aphasia-friendly format, and read aloud by the researcher. PWA thus had visual cues presented to them to take their time in thinking about the answer and responding. Items were presented in a written format and read loudly by the researcher. Hence, PWA who have difficulties reading written materials can benefit from the auditory cues, while PWA who have difficulties in auditory comprehension can benefit from the written cues.

When PWA had difficulties in expressing their views, they were offered pen and paper to draw or write if they wished to. They were also offered options in Talking Mats^{TM} for questions that they faced challenges in answering independently. A level of bias could be imposed because some participants faced challenges to expressed and used options provided on Talking Mats^{TM}. For example, some participants with aphasia faced challenges expressing what they want in relation to their communication and aphasia therapy; hence, they were offered options (please refer to *2.4.2 Aphasia-friendly interviewing materials* in chapter 2). To reduce the level of bias, all expressions of PWA were reported, be they those expressed using Talking Mats™ or those expressed through interviews. To ensure reliability of answers on the Talking Mats^{TM}, researcher explained the scale to PWA, and reminded them of it each time it was used. When PWA seemed unsure about some choices, the researcher pointed to the scale and asked yes/no and follow up questions (e.g. is reading something you want to work on or not? so this is not important to you?) to ensure PWA's responses and understanding.

To facilitate comprehension of PWA, the researcher repeated, rephrased, and clarified questions with related examples (e.g. Ok, why you did not tell her, for example, that there something I want to work on?) until researcher was assured that PWA understood the question. Moreover, researcher reflected on and summarised PWA's responses before going to the next question in the interview to ensure reliability of their responses (e.g. You mean you did not help her in choosing therapy goals). All data that presented PWA’s views and were collected using the supporting materials were retained to be analysed later as part of the interview scripts.

When PWA showed signs of fatigue or distress, or when they lost their attention, they were offered a short break from the interview. All PWA’s interviews continued without breaks, cancellation or rescheduling.

4.4.4 Collecting clinical case record data

Collecting data from PWA’s case records was completed after interviewing them. The researcher arranged with the SLTs responsible for PWA’s cases to meet and access case records. All case records were stored electronically and accessed by the researcher in the presence of SLTs. PWA’s case records which SLTs managed included admission reports, discharge reports, SOAP notes, and follow-up reports.

The researcher used the data extraction form developed previously and reported in chapter 2 (under *2.3 Developing a case record data extraction tool*) to document information from all available reports for each participant with aphasia. Demographic information, medical information and speech and language therapy session information were thus collected from the records of PWA.

4.4.5 Audio and video recording

All interviews with participants in this study were audio recorded. Audio recording was completed using a Sony digital audio recorder. All interviews were downloaded from the audio recorder to a password-protected hard drive within 24 hours and deleted from the audio recorder.

Only three participants with aphasia agreed to be video-recorded during the interview. To video-record participants with aphasia, a Sony digital camera was used. Similar to audio files, the three videos of PWA were downloaded from the digital camera to a password-protected hard drive within 24 hours and deleted from the digital camera. Because of the small number of participants with aphasia who agreed to video recordings, videos were not used during analysis in order to ensure consistency of the data analysed.

4.4.6 Participant confidentiality

All participants in the current study were assigned a numerical code to protect their confidentiality. PWA's numerical codes end with the letter 'p', family members' numerical codes end with the letter 'f', and SLTs' numerical codes end with the letter 's'. All paperwork and electronic files (written, audio and video files) include participants' codes rather than names. Participants' names and the assigned codes are saved in a separate document in a Google Drive account maintained by the University of Sheffield and accessed exclusively by the researcher and in an encrypted folder stored in a password-protected external hard drive accessed exclusively by the researcher. The university has approved Google Drive as meeting its data security and privacy requirements for sensitive information.

4.4.7 Data storage

Storing participants' data in this project followed a specific, rigorous plan so as to ensure confidentiality and adhering to ethical standards. Four categories of data were handled and stored safely following a plan developed prior to data collection. The categories include participants' names and assigned codes, case record forms, audio and video recordings, and interview transcripts. Figure 4.6 presents detailed information on data storage.

By the end of this project, interview transcripts, case note data, and video and audio recordings of the participants who agreed to store and use data in future research will be saved at the University of Sheffield. The data of participants who did not consent to that will be destroyed.

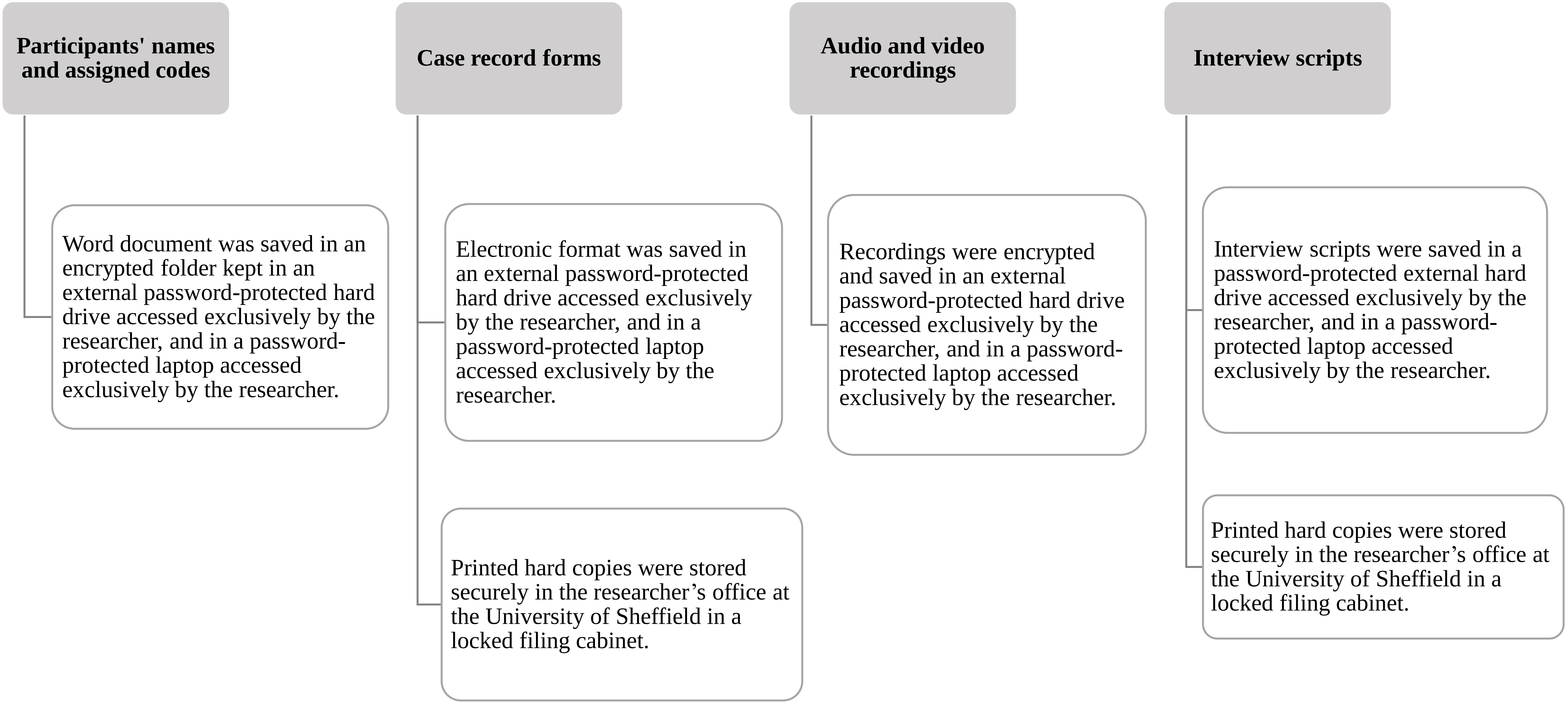
4.5 Data analysis

4.5.1 Overview

Interview and case record data were analysed using the analytical approach reported in detail in chapter 3 under *3.2 Selected analysis methods: Reflections and justifications,* and *3.4 Data analysis.*

Two datasets, including interviews and case record data from the three participant groups (PWA, family members, and SLTs), were analysed using an analytical approach that combined two methods. The two analytical methods aimed to explore the topic thoroughly. The analytical methods adopted include a thematic coding approach (Flick, 2014) and grounded theory techniques (Glaser & Strauss, 1967).

Interview data of the three participant groups were transcribed and analysed in the source language (Arabic) in order to preserve meanings and expressions reported in Arabic. Once the complete dataset had been transcribed, and all codes identified in Arabic, a translation approach following recommendations reported in the literature was utilised to translate Arabic codes into English. Section *3.3 Cross-language research and translation* in chapter 3 provides the full description of the translation process.



Participants' names and assigned codes

Word document was saved in an encrypted folder kept in an external password-protected hard drive accessed exclusively by the researcher, and in a password-protected laptop accessed exclusively by the researcher.

Case record forms

Electronic format was saved in an external password-protected hard drive accessed exclusively by the researcher, and in a password-protected laptop accessed exclusively by the researcher.

Printed hard copies were stored securely in the researcher’s office at the University of Sheffield in a locked filing cabinet.

Audio and video recordings

Recordings were encrypted and saved in an external password-protected hard drive accessed exclusively by the researcher, and in a password-protected laptop accessed exclusively by the researcher.

Interview scripts

Interview scripts were saved in a password-protected external hard drive accessed exclusively by the researcher, and in a password-protected laptop accessed exclusively by the researcher.

Printed hard copies were stored securely in the researcher’s office at the University of Sheffield in a locked filing cabinet.

Figure 4.6 Data storage plan

Data analysis resulted in identifying a comprehensive thematic structure that preserves the individuality of cases and reports the views of the three participant groups. Results are presented in chapter 6 and discussions of findings are reported in chapter 7. In chapter 7 and after discussing results, a conceptualisation of goal-setting within the Saudi context of experiencing stroke and aphasia is provided.

4.5.2 Analysis rigour

To ensure rigour of research and trustworthiness of findings, a number of steps were taken. These steps are reported in detail in section *3.5.1.6 Strategies to ensure trustworthiness of findings.*

As suggested in the literature, and to ensure the reliability of thematic coding, 10% of the data were extracted to be recoded via an intercoder reliability check (Campbell et al., 2013; Hodson, 1999). For this purpose, 86 data pieces from all participant interviews were randomly selected by the researcher. The data were divided into two sets and given to two Arabic-speaking researchers in the field of aphasia, in addition to a list of codes that were developed by the main researcher. This method was used to ensure that the reliability check covered a wide range and included all participant data rather than two or three interview transcripts. When the first or second coders were unsure and found that more than one code is suitable for a data unit, they were told to write them in order to discuss that later with the researcher. An agreement of 83.7% was achieved between the researcher and the first coder, and an agreement of 100% was achieved between the researcher and the second coder. Therefore, an overall agreement of 91.8% was achieved between the researcher and the two coders for the 86 data pieces. The disagreements between the researcher and first coder were discussed and the overall agreement percentage in this study was deemed to be acceptable.

4.6 Chapter summary

This chapter presented participants' characteristics, and provided an account of the research design, which aimed to collect qualitative data from three viewpoints (PWA, family members, and SLTs) in order to investigate goal-setting within the Saudi context of experiencing stroke and aphasia. This chapter also presented the data collection procedure and the data analysis approach in the current project. Chapter 5 presents pilot studies that were undertaken in this research.

Chapter 5 The pilot studies

5.1 Introduction

Chapter 5 presents the pilot studies undertaken in the current research. The chapter starts by reflecting on piloting in qualitative research. Then, pilot study I, which aimed to test the interview materials and data extraction form (reported in chapter 2), is presented. The final section of this chapter presents pilot study II, which aimed to test the thematic analysis method proposed in chapter 3.

5.2 Piloting in qualitative research

A pilot study can be conducted in order to examine the feasibility of a project, test data collection materials, assess participants' recruitment methods, identify barriers that might occur at any stage of the project, train the researcher in conducting interviews or focus groups, and assess the data analysis method proposed (Perry, 2001; van Teijlingen & Hundley, 2001).

There is a debate surrounding whether data collected in a pilot can be included in the main study, and whether pilot participants can be included in the main study with new data. Researchers involved in quantitative research have argued that if data collection materials were modified to be used in the main study, then the data collected before such modifications might be unusable (van Teijlingen & Hundley, 2001). Furthermore, van Teijlingen and Hundley (2001) mentioned that multiple exposure of participants to research materials is another area of concern. Pilot participants who are included in the main study will be exposed to the materials more than once, unlike the main study participants, which consequently might influence the responses of these participants. In qualitative research, however, it has been argued that researchers often can use part or all of their pilot study data to avoid having a small number of participants when recruitment is challenging (e.g. in a prison or hospital) (van Teijlingen & Hundley, 2001).

Kim (2011) advocates conducting pilot studies in qualitative research. Pilot studies, from Kim's (2011) perspective, allow for testing recruitment methods, being involved in the context as a researcher, reflecting on the necessity of objectivity, and, finally, modifying tools. Majid, Othman, Mohamad, Lim, and Yusof (2017) also advocate the importance of piloting in qualitative research. They attribute such importance to discovering methodological issues that could arise, such as recruitment and improving interview questions before the main study.

The following two sections present pilot study I, which was conducted in order to test the interview questions, aphasia-friendly interview materials, and data extraction form developed and reported in chapter 2, and pilot study II, which aimed to examine the analytical method selected in chapter 3 in order to identify any issues before analysing the main set of data collected.

5.3 Pilot study I

The following sub-sections present the pilot study aims, included participants' characteristics, and design. Then, the materials and procedure are presented and the following modifications are reported.

5.3.1 Aims

Pilot study I was conducted in order to test the data collection materials that were developed and reported in chapter 2. Since interviewing PWA could be challenging due to the presence of communication difficulties, it was necessary to test the interview materials developed and observe PWA's responses and interaction in relation to the materials. The specific aims of conducting a pilot study were as follows:

1- To test the interview questions, and aphasia-friendly interview materials developed for PWA and reported in chapter 2 under *2.4.2 Aphasia-friendly interview materials* and modify them as necessary before conducting the main study.
2- To test the case record data extraction form, and modify it as necessary before conducting the main study.

5.3.2 Participants of the pilot study

5.3.2.1 Inclusion and exclusion criteria

The selection of participants was purposive, as the inclusion and exclusion criteria reported in chapter 4 under *4.2.3 Inclusion and exclusion criteria* were given to SLTs through the supervising SLT in King Fahad Medical City.

5.3.2.2 Recruitment and consent

Recruitment followed the procedure reported in chapter 4 under *4.2.4.2 Recruitment*. To recruit PWA in the pilot study, the researcher asked the supervising SLT to nominate two PWA with mild and moderate to severe aphasia to be included in the pilot study. The supervising SLT distributed the inclusion and exclusion criteria to other SLTs providing services to PWA. The PWA were approached by their SLTs regarding the study and to obtain their verbal approval to meet the researcher. When both PWA agreed to meet the researcher in the study, the researcher met each participant in order to discuss the research. In the first session with 001p, the researcher met the participant along with her daughter, and in the first session with 002p, the researcher met the participant along with his daughter. The researcher discussed the project with each participant in the presence of the family member and the SLT, presented the information sheet and discussed it, and asked PWA and their family members if they would like to take it home and if they had any queries. Both PWA discussed the information sheet with their family members, asked the researcher some questions (e.g. This will not be video-recorded, right?) and agreed to participate.

For PWA, the consent form was then presented. The researcher discussed all items with PWA and their family members, assuring them that their name would not appear on any document and that they were free to participate or not. Both participants agreed to participate and signed the forms. Participant 001p refused to be audio-recorded due to cultural issues, as she did not want records of her voice to be retained by another person whom she did not know, which was respected by the researcher. Conducting the pilot with 001p without audio recording was acceptable at this stage because transcribing and analysing the content was not one of the aims at this stage, unlike in the main study. Participants who refused to be audio-recorded in the main study would be excluded. The participant's responses were transcribed during the interview, and photos of her responses on Talking Mats^{TM} were taken as well.

Family members of the two recruited PWA who fit the inclusion criteria did not agree to participate in the pilot study. Due to difficulty in recruitment and time constraints, it was decided by the researcher to test the aphasia-friendly interview materials with these two PWA, and test the interview questions with an available SLT and a family member of an eligible participant with aphasia. Since the aim of the pilot is to test materials rather than to analyse data, it was deemed to be acceptable that the PWA, family member, and SLT who are included in the pilot study are not forming a triad that includes a person with aphasia, his/her family member and the SLT responsible of the case.

The family member recruited in the pilot study was approached by the SLT in charge of his father's case. When the family member verbally agreed to participate, he met the researcher to discuss the information sheet and sign the consent form. The recruitment of SLTs was facilitated by the supervising SLT; thereafter, the researcher and recruited SLTs discussed the study and the information sheet to sign the consent form.

5.3.2.3 Screening PWA for inclusion

When both PWA signed the consent forms, the researcher asked if they would like to undergo the screening presently or if they would like to schedule it for another session. Both participants agreed to undergo the screening in the first session, and both preferred their family members to accompany them. The screening took place in an adult clinic therapy room and lasted around 10 minutes for both participants, both of whom were able to answer all questions. Detailed information on screening is provided in chapter 4 under *4.4.3.1 Screening PWA.*

For both PWA, all questions were presented on cards on Talking Mats^{TM}. The researcher asked a question and waited for their response. When participants experienced difficulties in answering, the researcher presented cards that included options related to the question, and guided the participants in selecting whether or not the options were preferable. Both 001p and 002p were able to answer all three questions; thus, they were included in the pilot study. The researcher was able to gather more information through the use of Talking Mats^{TM}, as in the third question, wherein both participants provided a wider view on their preferred activities. Appendix K presents a table of participants' responses, and Appendix L presents photos of their responses through the use of Talking Mats^{TM}.

5.3.2.4 Participants' characteristics

Participants in the pilot study included two PWA. Participant 001p is a 52-year-old female who was admitted to King Fahad Medical City in May 2018 after experiencing a stroke. Participant 002p is a 51-year-old male who was admitted to King Fahad Medical City in January 2018 after experiencing a stroke. Both participants are Saudi and married. Both of them presented with non-fluent aphasia based on informal assessment. Participant 001p presented with mild receptive and moderate expressive difficulties, while participant 002p presented with mild to moderate receptive and severe expressive difficulties. The family member (004f) included in the pilot study is the son of a PWA receiving inpatient speech and language therapy in King Fahad Medical City. He is a 36-year-old PhD holder from Riyadh. The SLT (008s) included in the pilot is a 28-year-old Saudi female also from Riyadh who delivers aphasia therapy to inpatients and outpatients receiving rehabilitation services in King Fahad Medical City.

5.3.3 Design

The pilot study was conducted in King Fahad Medical City (KFMC) in Riyadh with two PWA, an SLT, and a family member.

To achieve the aims of the current pilot study, the method reported in Majid, Othman, Mohamad, Lim, and Yusof (2017) was adopted. The researchers suggested the following steps in order to conduct a pilot study:

1- Identifying interview questions.
2- Experts reviewing initial interview questions.
3- Choosing participants.
4- Testing interview questions.
5- Reporting the modifications made for the main study.

Figure 5.1 presents the pilot study I design based on Majid, Othman, Mohamad, Lim, and Yusof's (2017) method.

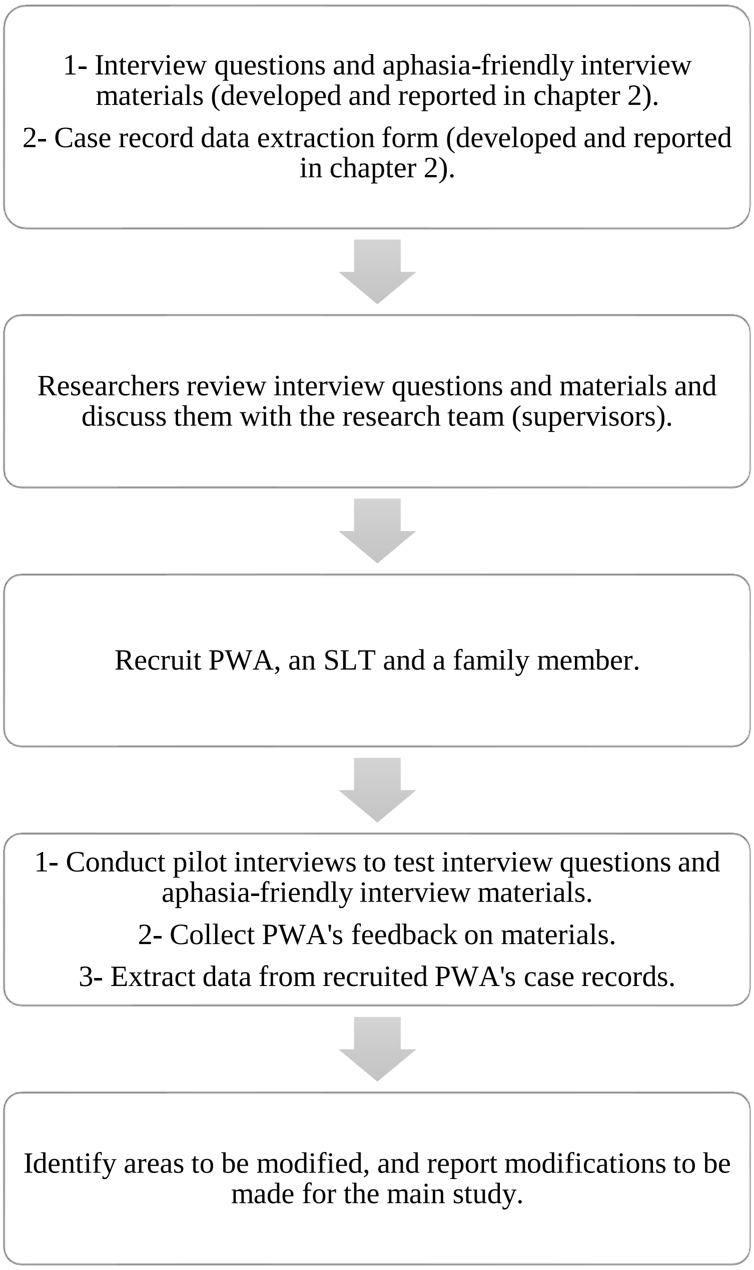


Figure 5.1 Pilot I study design adopted from Majid, Othman, Mohamad, Lim, and Yusof's (2017) study

Therefore, in the current pilot study I, the interview questions (developed for PWA, their family members, and SLTs), aphasia-friendly interview materials, as well as the case record data extraction form, which were all developed and reported in chapter 2, were trialled. Two PWA, one SLT and one family member were recruited to participate in this pilot study. Participants were interviewed, PWA were asked for their opinion on the aphasia-friendly materials, and areas of modification were identified and reported.

5.3.4 Materials and procedure

5.3.4.1 Piloted materials

In this pilot study, the interview questions, aphasia-friendly interview materials, and case record data extraction form were trialled.

Interview questions that were developed following the systematic review (reported in chapter 2 under *2.2 Developing interview questions*) were tested with two PWA, a family member and an SLT. Appendix E presents a table of the piloted interview questions. The aphasia-friendly interview materials reported in chapter 2 under *2.4.2 Aphasia-friendly interview materials* were also trialled in this pilot. As reported in chapter 2, all interview questions were simplified and written in a large font on postcard-sized, laminated, white paper. Questions were supported by written-answer choices as well as black-and-white drawings when suitable. Questions were presented on Talking Mats™. Pens and paper were available during the interviews if the researcher or interviewee needed to write or draw. Moreover, PWA's conversation was supported by the researcher when needed through reading questions and choices, repetition, rephrasing, gesturing, and confirming PWA's responses by summarising and reflecting. Appendix N presents photos of the aphasia-friendly interview materials used in the pilot study.

In addition to interview questions and aphasia-friendly interview materials, the case record data extraction form was trialled in pilot study I. Information on designing the form is presented in chapter 2 under *2.3 Developing a case record data extraction tool*, and Appendix G presents the developed and piloted form.

5.3.4.2 Interviewing procedure

Interviewing PWA, the family member and the SLT followed the procedure reported in chapter 4 under *4.4.3.2 Interviewing procedure* and *4.4.3.3 Variations in interviewing PWA*.

On the day after screening was completed, the SLTs of both PWA approached them again and informed them that the researcher would like to interview them. Both PWA agreed to be interviewed on that day. 001p preferred to be interviewed in the presence of her daughter, and 002p preferred the SLT to remain. Interviews took place in an adult clinic therapy room in King Fahad Medical City. Both PWA were able to communicate their thoughts throughout all questions with the help of Talking Mats™. Similar to the screening, all questions were presented on cards on Talking Mats™. The researcher asked a question and waited for the participant's response. The researcher presented cards that included options related to the question, and guided the participant in selecting whether or not the options were preferable when they experienced difficulties in expressing or elaborating. The pilot interview lasted around 30 minutes for each participant. When both interviews ended, the researcher asked participants for their feedback on the questions, pictures, supporting materials, and interviewing time.

Feedback was obtained at the end of the session and not after each section of the interview, mainly for two reasons. The first reason was that of obtaining an accurate estimate of the interviewing time, and whether it suited the abilities of PWA. Meanwhile, the second reason was that of avoiding confusing PWA during interviews by switching their thoughts from the main topic to giving feedback after each section of the interviewing schedule. A separate set of aphasia-friendly materials were developed in order to facilitate PWA's expression when providing their feedback. Four questions were asked to PWA in order to collect their feedback after the pilot interview. Questions asked to PWA are provided in Appendix O in an aphasia-friendly format. PWA were asked whether the interview questions were clear, pictures were clear, supporting materials (pens, paper, pictures, scales) were helpful, and interviewing time was appropriate.

Participants' responses were audio-recorded (except for those of 002p, who did not agree to be audio-recorded), transcribed verbatim, and stored securely according to the storage plan reported in chapter 4 under *4.4.7 Data storage*.

5.3.4.3 Case record data extraction form

The researcher asked the supervising SLT for access to participants' records in order to collect information. The supervising SLT referred the researcher to the SLTs who are responsible for the two participating PWA's cases. Participant 002p's record included an assessment report and two progress reports, while 001p's record included only an assessment report. Information was collected manually, and electronic formats of the data extraction forms were filled.

5.3.5 Results and amendments to materials

PWA were able to understand and respond to the interview questions; however, some minor difficulties were encountered. When PWA faced difficulties in understanding a question, the researcher used the strategies reported in chapter 4 under *4.4.3.3 Variations in interviewing PWA*. PWA's responses to questions are provided in Appendix M.

To facilitate understanding of the first question during the interview (Tell me about your aphasia), the researcher prompted PWA by specifying a point in time (when you first had it). To continue discussing a specific point in time and to avoid confusing PWA, they were prompted to discuss their communication also when they first experienced aphasia (e.g. When you first had it, were you able to request by speaking?). Afterwards, PWA were prompted to discuss their communication at present.

When PWA were asked “What did you want or hope when you first had aphasia?”, their answers were general (e.g. When it first happened, honestly, I mean, honestly, thanks to God, when I noticed that I was better; just to see them); therefore, a prompt related to their communication was needed.

When they were asked “Do you work in speech and language therapy to achieve these goals?” in relation to the previous question, wherein they were asked about their own goals, both 001p and 002p answered “yes”. Then, when a clarification probe was asked (What activities do you do in therapy?), they faced some challenges in remembering and specifying activities.

With the use of Talking Mats^{TM}, PWA’s expression was facilitated and their responses were expanded. However, some difficulties were encountered when presenting some option cards (e.g. To make your family members understand you when you talk); thus, they were simplified orally by the researcher (e.g. That family understands you when talking).

PWA were able to respond to the aphasia-friendly interview materials and to answer the interview questions with the help of the aphasia-friendly materials. The interactive nature of the Talking Mats^{TM} framework allowed PWA to be more engaged during the interview. The materials assisted participants in following questions visually and choosing options when needed. Presenting a visual reference to PWA in the form of written questions and pictures facilitated comprehension and more elaboration on the written elements. Supporting PWA's answers with options facilitated their expression and also provided PWA with the opportunity to elaborate when they desired. Photos of their responses on Talking Mats^{TM} are provided in Appendix N.

The researcher asked participants for their feedback after the pilot interview, both of whom responded that the questions were clear and that they understood them. In addition, they stated that the pictures were clear and that the supporting materials were helpful. The pilot interview lasted around 30 minutes and the participants stated that the length of the interview was appropriate. Both participants provided positive feedback on all aspects.

Following are some changes to each question to take forward in the main study for PWA in order to decrease ambiguity:

1- The question "Tell me about your aphasia" will be reworded as "Tell me about your aphasia when you first had it" so as to make it specific and clear to PWA that we are referring to a certain point in time, as it was noticed that the question is general and that it could be challenging for participants with aphasia to answer it without some specifications.

   The prompt "your communication" will be used to ask about communication when PWA first experienced stroke. Options will be presented in such a way as to ask about how PWA used to communicate at that time.

   A separate question — "Tell me about your communication now" — will be presented after the first question with a scale of very good to very poor and with four options (reading, writing, comprehension and expression).

2- The prompt "when you first had aphasia" will be added to the second question, i.e. "Tell me about the speech and language therapy you had before".

If the current therapy is the first therapy, no further options will be presented, as later questions will address this matter. Meanwhile, if the participant underwent previous therapy, options will be presented in asking about areas upon which they worked, including reading, finding words, completing sentences and producing the correct sound.

3- Regarding the third question, it was confusing for the participant to have the same option cards in the third and fourth questions. Thus, the question "What did you want or hope when you first had aphasia?" will be prompted by "what things you wanted in your communication".

4- The fourth question will be reworded as "What do you want or desire now?". Option cards that contain general goals in relation to communication will be presented. The wording of these option cards will be simplified, as difficulties in understanding some sentences were noticed (e.g. "To make your family members understand you when you talk" to "That family understands you when talking").

5- The fifth question — "Do you work in speech and language therapy to achieve these goals" will be reworded as "Tell me what you do in speech and language therapy now", as it was noticed that the original closed-ended question was confusing and could lead the participant to answer with "yes", even if they might not have been working on the goals.

Another question — "Is there anything else you want to do in therapy?" — will be added after the fifth question.

6–10- No changes will be made to questions 6–10, as no difficulties were observed.

Regarding the family member (004f) and the SLT (008s), they were able to answer all interview questions; no difficulties were encountered by them with regard to understanding the interview questions. During the interview, follow-up clarification questions were used with the family member and the SLT (e.g. “How did you deal with that?”, “To express by any means or by speaking?”) to expand on their responses.

No difficulties were encountered when transferring all demographic information, medical information and therapeutic goal information from participants’ records to the form. In addition, no extra essential information was found in PWA’s case records that did not fit any section of the data extraction form. The data extraction form provided a straightforward visual representation of participants’ information and was retained in its original form. Please see Appendix P for a sample of a completed section from 002p’s data extraction form.

PWA’s data (001p and 002p) were not included in the main study because modifications were made to their questions and because complete triad recruitment was not facilitated since their family members did not agree to participate in the study. Since no major modifications were made to family members’ and SLTs’ interview questions, and since the father of 004f and the person with aphasia working with 008s are eligible participant to be included in the study, it was decided by the researcher to include the data of 004f and 008s in the main study in order to avoid losing participants because the number of eligible participant was limited and recruiting triads (PWA, their family members, and SLTs) was challenging.

5.4 Pilot study II

The following sub-sections present pilot study II’s aims, included participants’ characteristics, and design. Then, an overview of the data analysis is reported in addition to reflections on that process in order to consider areas of difficulty in the main study analysis.

5.4.1 Aims

Pilot study II was conducted mainly to assess the proposed thematic analysis approach reported and justified in chapter 3, prior to analysing all data collected. This was decided so as to capture technical and analytical issues before handling all data together in order to avoid potential problems arising when a dataset is large and time is restricted. Following are the specific aims of conducting pilot study II:

1- To deeply analyse the first case in each group in order to develop initial thematic domains to cross-check with other cases, as Flick (2014) suggested.

2- To assess whether the proposed analysis approach provided rich and comparable data between participants.

3- To identify potential analytical problems that might occur at any stage (from data management to reporting results).

5.4.2 Participants' characteristics

A female with aphasia, her mother and her SLT constitute triad 2, which is included in order to test the analytical method in the current pilot. All three participants in the triad are Saudi females from Riyadh. Their age range is between 28 and 45 years. The participant with aphasia received outpatient speech and language therapy at King Fahad Medical City and presented with non-fluent aphasia after a middle cerebral artery stroke.

5.4.3 Design

A one-triad case design was adopted. The data collected in the main study is used in the current pilot because the main aim is to test analytical methods. The thematic analysis techniques reported in detail in chapter 3 under *3.2 Selected analysis methods: Reflections and justifications*, and *3.4 Data analysis* were used to examine the data collected from one triad of participants (including a person with aphasia, her family member and her SLT). Data pertaining to the triad was collected through semi-structured interviews, aphasia-friendly materials, a background form, and a case record data extraction form. All information in relation to materials is reported in chapter 2 (Development of research materials), whereas information in relation to data collection methods is reported in detail in chapter 4 (Research methods). Figure 5.2 below presents the general design for pilot study II.

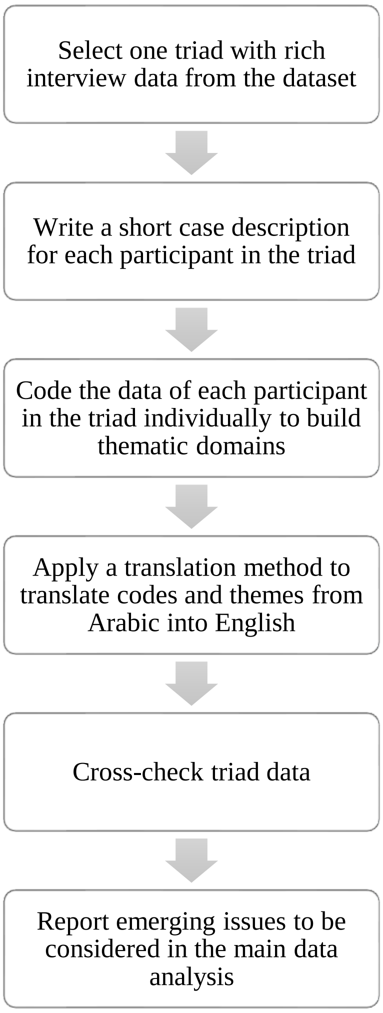


Figure 5.2 Pilot study II design

5.4.4 Methods

Data was coded in line with the methods outlined in chapter 3 under *3.4.1.4 Thematic coding according to Flick's (2014) approach.* Therefore, brief case descriptions were written for each participant. Then, open and selective codes were assigned to data. After the coding process, codes and thematic domains were translated from Arabic into English for further interpretation, following the approach suggested in chapter 3 under *3.3 Cross-language research and translation*. No major discrepancies that could affect the meanings of data were found between the translated versions. Some differences were found between versions in respect of using terminology in words, including: networking, session, barriers, and unwilling.

5.4.5 Results

5.4.5.1 Case descriptions

As described by Flick (2014), thematic analysis starts with writing a brief case description on the case. Following are the three case descriptions written for the triad members included in the current pilot.

The participant with aphasia: 006p

"She is the doctor and she understands what I want"

> *006p is a 28-year-old Saudi female. 006p experienced a left middle cerebral artery stroke and was admitted to the rehabilitation hospital in 2017. 006p received inpatient rehabilitation services from March to May 2017, and then started to receive outpatient speech therapy sessions from July 2017. As an inpatient, 006p was seen daily or four times per week for 30 minutes. 006p experienced stroke suddenly. At the time of stroke, 006p was enrolled at the*

university and studying Business for her bachelor's degree. Based on the informal speech and language assessment, 006p was diagnosed with non-fluent aphasia and mild to moderate apraxia. 006p has a positive view on her own communication skills, expressing that her reading and writing are good and that her expression and comprehension are very good. For 006p, speaking, continuing education, and finding a job are goals that the patient desires to achieve. 006p trusts her SLT in setting therapeutic goals. 006p believes that networking with people is a factor that might enhance communication skills for people with aphasia.

The mother: 007f

"I want her to be strong enough to live her life naturally"

007f is a 45-year-old Saudi female. 007f is a housewife and the mother of patient 006p. 007f is the main caregiver for her daughter, as she attended the different rehabilitation inpatient and outpatient sessions with her. 007f expressed experiencing some confusion when her daughter was experiencing stroke, as they did not receive satisfying details on the diagnosis. For her daughter with aphasia, 007f's goals comprise speaking, physical health, and obtaining a job. 007f wants to give her daughter strength and for her to be fearless, as she thinks that her daughter's fear of people's judgment is hindering her improvement. 007f noticed much improvement in 006p's communication skills as a result of therapy, attributing that to the SLT's manner and the patient's cooperation.

The SLT: 008s

"We usually never give up on severe patients"

> *008s is a 28-year-old Saudi female speech and language therapist working in King Fahad Medical City. 008s has a bachelor's degree, and is licensed by the Saudi Commission for Health Specialities. 008s's interest lies in acquired communication disorders for adults and children. She worked with 006p on improving expressive, reading, writing and academic skills. 008s was willing to hear from 006p and her family and discuss the plan with them during the intervention period. She believes that the participation of PWA and their families specifically in choosing goals is fundamental in speech therapy. As an SLT, a core care value for 008s is that of not giving up on patients, even in severe cases.*

5.4.5.2 Thematic domains

Using the thematic coding process proposed by Flick (2014) resulted in the development of thematic domains for the participant with aphasia, her mother, and the SLT in charge of the case (please refer to Appendix Q). Amongst the participant with aphasia, her mother and her SLT, five domains overlapped. The overlapping themes include: The impact of stroke and aphasia, Hopes, Participation, and Satisfaction and progress.

"The impact of stroke and aphasia" is a thematic domain that appeared in all participants' interviews. This theme is related to the views of participants on how stroke and aphasia affected their lives. All participants mentioned in their interviews that the medical condition had an impact on the person with aphasia's communication skills and her physical and psychological status. "Hopes" is a thematic domain related to the goals of the participant with aphasia and her family member, in addition to the SLT's awareness of the goals of her patient and her family member. "Aspects of provided intervention" is also a thematic domain that includes the intervention components that were provided to the patient with aphasia, the themes present in specific goals, and activities that were worked upon in speech therapy sessions. "Participation" is another thematic domain that reflects the participation level of the family member in the rehabilitation process. In addition to that, this theme focuses on the participation of the patient and their family member in setting the therapeutic plan with the SLT, as well as the importance of their participation from their own perspective. "Satisfaction and progress" is also a thematic domain that focuses on the participants' impression of the patient's progress and their satisfaction with the speech and language therapy provided.

A deep interpretation of the data was not conducted because there is a need for data cross-checking and the refinement of themes based on a larger set of data.

By examining initial thematic domains of the three participants, a glance at the stroke and aphasia experience in addition to the triadic dynamic in relation to goal-setting could be captured. Stroke and aphasia affected the psychological and communicative aspects of 006p's life. Moreover, the condition imposed an emotional burden upon the mother, as she experienced confusion and negative feelings. These effects of stroke and aphasia are similar to what is reported in the literature. It has been reported that caregivers could experience negative feelings of worry and being overwhelmed (Grawburg et al., 2013b; Luker et al., 2017; Visser-Meily, Post, Riphagen, & Lindeman, 2004), and that psychological distress could be present in PWA who survived stroke (Code, Hemsley, & Herrmann, 1999; Code & Herrmann, 2003).

The initial thematic domains also suggest that 006p and her mother were involved in discussions on goals with the SLT. The SLT mentioned that 006p relied on her goals at the beginning, but then when the patient became more verbal, discussions took place. The SLT listened to and addressed the needs of the patient and the mother. The SLT addressed goals that were impairment-based, including naming pictures, as well as functional goals including academic skills and life scenarios. There are signs of a positive relationship between the triad members, as it is based on trust and positive manners attributed to the SLT.

The three participants reported similar therapeutic goals. This could be related to the fact that the patient in this triad did not have a severe form of aphasia that impaired her communication with the SLT. It has been reported in the literature that the severity of the case plays a role in goal alignment (Kuluski et al., 2013; Rohde et al., 2012). Furthermore, this could be related to the involvement by SLTs of 006p and her mother in discussions on goals and needs. The positive therapeutic relationship could have played a role, as it was reported in the literature that impaired communication could hinder the participation of patients and families (Rosewilliam, Sintler, Pandyan, Skelton, & Roskell, 2016).

The SLT’s conceptualisation of therapeutic goal matches Wade's (2009) definition, according to which goals are seen to be the future state and the steps that lead thereto. This perception of goals was also seen amongst some SLTs in Hersh et al.'s (2012a) study, as they also viewed goals as being a series of steps.

There is a need to understand the bigger picture by studying all participants’ data as a next step, followed by developing an overall thematic structure for a thorough understanding of the studied topics.

5.4.6 Discussion and amendments to the main study

The current pilot (II) was conducted in order to develop thematic domains related to one triad of participants (a person with aphasia, their family member, and the SLT). By doing so, the pilot aimed to examine the thematic analysis method proposed, as well as assessing whether the analytical approach would provide rich data for the purpose of the whole project. What is more, pilot II aimed to identify potential technical issues that might arise when starting to handle the dataset.

In the current pilot, Flick's thematic analysis method was used to explore the topic (Flick, 2014). A challenge was faced in this pilot during the phase of data coding. When data was coded at a detailed level in ATLAS.ti, difficulties were encountered when the researcher wanted to retrieve quotations based on the codes. Therefore, it has been decided that code groups will be used to code a larger amount of data in ATLAS.ti so that data retrieval becomes more practical in the software. In order to preserve all code levels, Excel codebooks were exported for each member in the triad separately to add sub-codes. In future analysis for all participants in the study, the same procedure will be applied separately for each individual, wherein Excel codebooks will be exported to add sub-codes.

It was observed also in pilot II that analysing each triad of participants in one ATLAS.ti project might not be practical in the main study, as this will hinder within-group cross-checking. Therefore, it was decided that each participant group's data (PWA, family members, and SLTs) will be imported in a separate ATLAS.ti project so as to facilitate within-group data cross-checking.

Flick's (2014) thematic coding approach facilitated a deep exploration of each participant's case, as well as a comparison of cases in order to capture commonalities and differences in the overall experience. The approach allowed searching for comparative dimensions and developing initial thematic domains for each participant where overlapping domains emerged; hence, facilitating understanding participant groups' views on the same issues. When exploring the larger dataset in the main study, more refined overlapping domains will emerge within and between groups. Therefore, a deep exploration of the topic from different viewpoints will be achieved. This approach allowed exploring and preserving individuals' experience, as well as including that experience in a wider image that presents participant groups' viewpoints.

5.5 Chapter conclusion

To conclude, piloting in qualitative research can be designed based on research requirements and can allow detecting areas to consider in the main study. This chapter aimed to present piloted aspects in the current research. The first pilot study aimed to trial interview questions and aphasia-friendly interviewing materials developed for PWA. Pilot study I resulted in modifications to PWA interview questions that will be carried to the main study. The second pilot study aimed to assess the thematic analysis approach. Pilot study II resulted in identifying technical issues to consider in the main data analysis. The following chapter presents the results of the main data analysis.

Chapter 6 Results

6.1 Introduction

This chapter presents the results of the data analysis which was reported in detail in chapter 3 and conducted in order to achieve the aims of the project. This chapter starts by presenting the comprehensive thematic structure that was developed by utilising the analytical approaches explained in Chapter 3. Then the chapter presents and discusses themes individually in separate sections, and ends by presenting a chapter summary that synthesises main findings to be discussed in chapter 7.

Each theme section provides an in-depth description of the theme from the viewpoints of the three participant groups (PWA, their family members, and SLTs). Extracts of participants' responses are provided in each theme to support data analysis and findings. A detailed structural presentation of each theme is provided at the beginning of each section in order to clarify which views contribute to it. Venn diagrams are presented within sub-themes or at the end of sub-themes to highlight results from different views.

In the following sections, participants' identities are protected and not identified; thus, assigned codes are reported rather than their names. Assigned codes containing the letter "p" (e.g. 003p) represent PWA's responses, while codes containing the letter "f" represent families' responses and "s" those of SLTs. PWA's extracts are highlighted in green, families' extracts in blue, and SLTs' extracts in orange.

6.2 The comprehensive thematic structure

The comprehensive thematic structure includes six major themes that were identified from analysis of all participants' data. The comprehensive thematic structure that holds all participants' views (PWA, their family members, and SLTs) is presented in Table 6.1.

The thematic structure includes six themes. Within each theme, results are presented under sub-themes from different participants' view. All themes hold three participant groups' views (PWA, their family members, and SLTs), except theme one which holds views of PWA and their families regarding their experience of stroke and aphasia, and theme three which holds only SLT's views on their process of setting therapeutic goals in aphasia rehabilitation.

The major six themes include Stroke occurrence and the social context, The impact of stroke and aphasia, Identifying therapeutic goals, Participation in goals-setting, Expectations in aphasia therapy, and The nature of goals in aphasia therapy.

6.3 Theme one: Stroke occurrence and the social context

Theme one reflects the views of participants on their experience of going through stroke as a sudden life change. Theme one also provides participants' views on being part of society and experiencing a medical condition that has a clear impact on different aspects of their lives, including communication skills.

The details of theme one are as follows:

- Sub-theme 1: Sudden life changes.

- A sudden occurrence and confusion.
- The challenge for families.
- Coping with the condition.

Table 61. The comprehensive thematic structure showing themes, sub-themes and participants views

Major themes	Sub-themes	Participants' views
Theme one: Stroke occurrence and the social context	Sub-theme 1: Sudden life changes	-A sudden occurrence and confusion -The challenge for families -Coping with the condition
	Sub-theme 2: Knowledge of stroke and aphasia among society	-Insufficient knowledge -The need for awareness
Theme two: The impact of stroke and aphasia	Sub-theme 1: The impact on PWA	-Physical abilities and activities -Communication skills -Social participation -Psychological well-being
	Sub-theme 2: The impact on family members	-Social participation -Psychological well-being
	Sub-theme 3: Changes in family dynamics	-The impact on familial relationships -Family support for PWA
Theme three: Identifying therapeutic goals	Sub-theme 1: Individuality of the case	-PWA's abilities -Functional needs

	Sub-theme 2: Goal achievability	-Small steps to achieve goals -Realistic steps
	Sub-theme 3: Involving PWA and their family members	-Discussions to incorporate realistic goals -Recognising PWA's and their families' goals
Theme four: Participation in goal-setting	Sub-theme 1: The extent of participation in goal-setting	-Sharing personal goals -Trusting SLTs as decision makers
	Sub-theme 2: Factors influencing effective participation in discussions about goals	-Condition-related factors -Knowledge of stroke and aphasia -Family presence in therapy sessions -Service-related factors
Theme five: Expectations in aphasia therapy	Sub-theme 1: Matched and unmatched expectations	-Matched expectations and effective participation -Unmatched expectations and negative impact on aphasia therapy
	Sub-theme 2: Managing expectations	-Reconciling goals -PWA and family education
Theme six: The nature of goals in aphasia therapy	Sub-theme 1: Goals for PWA	-General well-being goals -Impairment-based goals

		-Activity-related goals -Effective communication goals -Social participation goals -Service-related goals
	Sub-theme 2: Goals for family members	-Education and strategies to support PWA -Home exercises

- Sub-theme 2: Knowledge of stroke and aphasia among society.

- Insufficient knowledge.
- The need for awareness.

A detailed structure of theme one, which illustrates results and contributing views, is presented below in Figure 6.1.

6.3.1 Sub-theme 1: Sudden life changes

In this sub-theme, PWA and their family members shared views on their own experience of undergoing stroke and the emotions that emerged at the moment of occurrence. For both PWA and family members, the sudden occurrence of stroke and the confusion that was present in the situation were the two main issues that emerged. The family members experienced some challenges while dealing with stroke as a sudden medical condition that occurred to their loved ones. Both PWA and their families reported signs of coping with the new condition.

6.3.1.1 A sudden occurrence and confusion

The experience of stroke from the viewpoints of PWA and their families focused on the situation of stroke occurrence and the feelings that they experienced at that moment when stroke occurred suddenly. A sudden occurrence and confusion were experienced by PWA and their families.

While one participant with aphasia reported experiencing a sudden disruptive occurrence that they did not expect, others were unable to recall the moment. 009p reported his experience of a sudden occurrence in a social gathering while he was with friends, while 003p expressed that everything just happened suddenly.

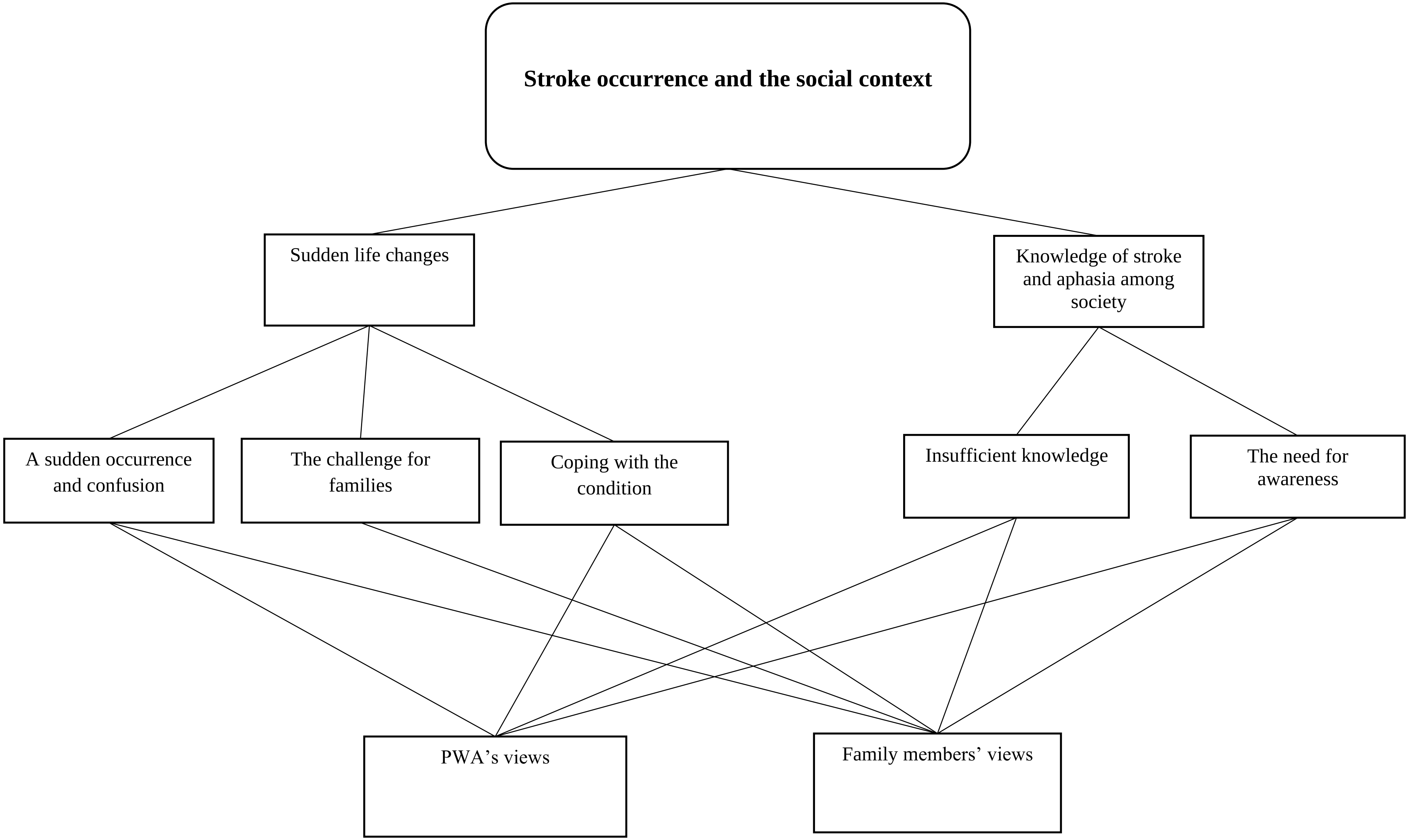


Figure 6.1 Theme one details and contributing views

009p: When stroke came, I do not know, I swear, it came and I was with my camels and by chance my friends were coming, and the bleeding happened. I swear the bleeding took a long time [inaudible segment].
HA: And straightaway they took you to the hospital?
009p: Straightaway, God bless them.

HA: Tell me about the stroke when you first had it.
003p: [inaudible segment].
HA: I mean at the start, yes like.
003p: At the beginning, it was sudden.
HA: It was sudden?
003p: It was sudden, that is it.

Other PWA reported an inability to remember the moment, as they woke up in the hospital after a stroke induced coma.

0017p: No not normal sleep [inaudible segment]. I do not remember anything.
HA: You do not remember anything?
0017p: Nothing.

0024p: The day I had the aphasia, I do not remember, because I was in coma.

Confusion was part of the experience of undergoing stroke for PWA and their families. Confusion was present for two main reasons: undergoing stroke and the inability to recognise its symptoms, and the need for information in the diagnosis stage. 0019p experienced confusion surrounding the symptoms for a period of time before knowing that these were signs of stroke. He expressed that he was unable to recognise himself anymore and was sure that something was happening but was unable to identify it.

0019p: Now I am walking like so, I swear it feels like it is not me, the one who knows himself like so [inaudible segment].

HA: At that moment, did you know that there is something not right going on?
0019p: I do not know what it is, what is it? I do not know, what is it? I do not know ... what is stroke? I do not know it.
HA: But there is something different.
0019p: Yes there is something strange in the brain. I said that to my wife [pause] what time is it now, maybe it is six o'clock.

Since 0019p did not know that he was experiencing symptoms of stroke, he was confused as to the reasons behind his physical weakness at the moment of stroke. Such uncertainty and confusion led the person with aphasia to link the weakness with his masculinity.

0019p: "You are a man, how did you let the water fall from your hand, no, get it again and hold it in your hand" No, there is something like, I said no there is a problem I do not know what it is, I do not know.

0022p experienced confusion related to symptoms at the moment of stroke, and did so again when she woke up in the hospital. At the moment of stroke, 0022p experienced a strong feeling of thirst.

0022p: No at first my husband came and later my son, oh my God as I was sitting, I say I want water, but to myself, I want water, I want water.

0022p was unable to understand her spouse's reaction at the time of stroke, when she thought that she was only thirsty. She explained that her spouse tried to check whether she was choking on something instead of giving her water as she was thirsty. As a result of the spouse's behaviour at the moment of stroke, as well as her mixed emotions and confusion, 0022p sensed hurt feelings and expressed that she would never forget that moment.

0022p: And then, you know, later my husband made a move, I swear I do not [trying to say forget] [sigh], no I do not.
HA: Do not forget it?

0022p: It is like there is something weird going on, there is something going on, so why, and even my son, I am at that time emmm, I swear everyone fear God.
HA: Were they trying to make you drink water?
0022p: No nothing, they did not give me water, nothing, it does not open, ok there is nothing in my mouth.
HA: They were opening your mouth to see what is in it?
0022p: Yes, yes, and by the way, it is so that you know, ok, it is for the one who are in my situation [pause]. Oh my God no harm comes their way.

In the hospital, and when her family started to visit her, 0022p was confused and it was difficult for her to process the situation.

0022p: I myself did not know I had a stroke; this is the first thing. The second thing is why! I mean when my mother and sister ‘thank God you are ok’, sigh, how could I tell you.

Furthermore, 0019p reported confusion and uncertainty regarding the diagnosis of his condition, although he visited the hospital when he was experiencing some signs that he could not identify. He reported that the hospital did not investigate his case thoroughly and the possibility of experiencing stroke until the physical symptoms were obvious and severe.

0019p: [inaudible segment] Your turn, I said ok, “what is up with you?” I said, doctor, there are things does not make sense as such and such, there are things, everything last night did not [inaudible segment] the speech opened [able to process] and then quiet and then opened and today opened. The doctor said ok, if it comes a second time,
HA: If it comes a second time?
0019p: I come back again. I said no sir, when I am finished and dead and finished I come back again here? this is not right, good bye.
HA: You did not do tests with them?
0019p: Nothing absolutely nothing, he told them I go home, that is it. I said what kind of a doctor is he. Let me go and what is written for me to happen it will happen.

Being given aspirin with a lack of information on the diagnosis and treatment plan was confusing to 0019p. He referred to such a lack of clarity as being due to the lack of physicians' awareness.

HA: To have more awareness; the society must understand this condition?
0019p: Yes, very much they must understand, I mean the doctor here, the stroke specialist, says, before the stroke [inaudible segment] four tablets for what [inaudible segment] blood.
HA: Aspirin for the blood.
0019p: Yes, four tablets only, after that I went to the hospital, they said it is like that. Before, maybe he had a major stroke. I called upon the doctor in the ___Hospital, and he did not tell me anything; the second time it comes back again. I said, when I am dying, I come back! no.
HA: You mean even some of the doctors need to have some awareness?
0019p: Yes, yes, yes.

Family members reported a sudden unexpected occurrence and confusion as well. A son of a person with aphasia expressed that stroke occurred suddenly to his father in a social gathering. The family discovered that the father was suffering from three clots; however, the symptoms were not evident until the person fell down unconscious.

0010f: And there were friends coming from ______(a city in Saudi Arabia), coming here for a break in ______(a city in Saudi Arabia) and then to take my father with them to a reconciliation gathering in Kuwait. When they arrived at my father's home at dusk, my father did not turn the light for them and did not greet them, the important, they called on my father to lead them in the prayer, my father came and lead them in the prayer, he did the first Rak'ah (Kneeling) and then the second Rak'ah and in the third Rak'ah my father fell down. They carried him and took him to ___ Hospital, here in ______(a city in Saudi Arabia). The day they took him to ___Hospital, the doctor came, sigh, the doctor there [inaudible segment] and said your father is here because he had three strokes.

A mother of a person with aphasia also expressed undergoing the experience with negative feelings, as it happened unexpectedly overnight.

007f: I was so upset, I mean there was nothing with her and between a day and a night she fell, that is it, I mean she fell like a dead person and this is what upset me. Praise to God, we stayed one month and half like so, and when she uttered, we were so happy, thanks to God, I mean even though speech was slow, but thanks to God it is better, even though I would like it better than this.

As 0019p and 0022p experienced confusion surrounding the symptoms of stroke, confusion with respect to the stroke diagnosis also occurred among PWA and their families. A mother of a participant with aphasia reported confusion and uncertainty that everyone experienced in the family. The family were not aware that 006p was experiencing stroke. The hospital that provided the initial treatment did not give enough information about the diagnosis and treatment, whereby leaving the family in a state of confusion. With regard to resembling a table and a dead person, it was the mother’s way of remembering the situation and viewing her daughter at the moment of stroke. Such uncertainty surrounding the diagnosis and the sudden occurrence of stroke left the mother feeling distressed in the situation.

007f: When we went to them, she was being treated at their centre, we made the tests for her and they gave her medicine. The medicines are the one I suspected; however, her father and brother forbade me from launching a complaint case against them and it is in my right to do so. When we went to the centre, they only gave her Aspirin, and the Aspirin I gave it to her at home when first she got the stroke. I did not know it was a stroke, I and her father gave her the Aspirin because we did not know what happened to her. When we lift her up, she was like a table, like a dead person. We took her back to them and asked them what happened to her, they said we do not know, we do not know. After the consultant saw her, he said maybe she suffered from a stroke, that means, it was not a hundred percent true hospital. I was so upset I mean there was nothing with her and between a day and a night she fell, that is it, I mean she fell like a dead person and this is what upset me.

6.3.1.2 The challenge for families

With a sudden life change, families of PWA expressed undergoing some challenges including, the difficulty of the experience in general, the difficulty in managing the medical condition and the difficulty in communication.

The family members expressed that the whole experience of seeing their loved ones undergoing stroke was difficult.

0012f: Of course, the experience is very hard, of course on my family and on me personally.

0014f: I swear it is hard, I mean it is really hard experience.

Stroke causes sudden life changes, 0014f reported that she only wants live normally as before, and go back to her home city in Eastern region because her husband was receiving rehabilitation services in Riyadh.

0014f: I mean, to go back home and live my normal life [pause].

As part of dealing with a new experience, family members had to deal with a medical condition of which they did not have previous knowledge.

0010f: All our family, my father and my mother, none had a stroke, only my father this time, do you know now, that is all.
HA: You mean a new thing in your family.
0010f: A new thing on our family.

They had to control a medical situation to which they had not been exposed previously. For some family members, managing the medical condition before receiving rehabilitation services was a burden.

0020f: The period when he was outside, he had four spasm episodes, I could not control the situation.

0020f: It was hard period, I mean from physiotherapy to speech therapy, I mean the period when he was at home before going to the hospital. When we brought him to the hospital, the burden is halved, even his communication and walking has improved well.

The majority of family members faced some challenges when communicating with their loved ones who had experienced stroke. Understanding PWA’s needs and waiting to convey their messages were major areas of difficulty.

0020f: It was something hard for all of us specially my children. I mean even my youngest sone, he was two years old, he was repeating his words twice and three times so his father can understand. The whole house was surprised, but thanks to God the child did not fear his father.

0028f: I swear, the experience at the beginning, of course, was hard, because we did not understand what he wants or what he wishes, it is as if you, for example, use words about the things that can communicate a piece of information to him.

0025f: Of course, at the beginning we were tired, I mean we made an effort to communicate.

The fact that some families were unaware that stroke might cause difficulties in language expression and comprehension might have added another level of challenge to family members. As in the extract below, family members did not realise that their father had aphasia until he was frustrated because of the difficulty of expression.

004f: OK, at the beginning it was difficult on the family to realise that a family member is having aphasia. We did not know he had aphasia and we did not know he had a problem. We were expecting that he comprehend and understand what we want from him, but as time went by, it became apparent that he was pointing to most of the things, and sometimes he reaches a high point of tension as if he wants to say something but does not know how to say it. After that he started to show some expression; sometimes he holds his mouth, meaning he wants to say something but does not know how. At that time, it became clear to us that, for sure, he had aphasia.

004f: It is of course, after we understood the situation that he must find alternative methods that enables him to express the word he try to say, because we knew he knows the thing but the problem he cannot say it, so we were trying to give him part of the word to enable him say the word or we show him the thing and then ask him what is the name of it.

6.3.1.3 Coping with the condition

People adapt differently to sudden life changes. After experiencing stroke and facing challenges after the occurrence, PWA and family members showed signs of coping to their condition, including having faith in God, believing in proactivity, and having patience.

For PWA, acceptance is shown in how some expressed that they depend on and have faith in God as this situation is already written or out of human control.

0019p: They said stroke, I said praise to God, this is what is written by God [inaudible segment], ok, praise to God. What could I say about it except praise to God, that is all, as long as our family is fine, and the household is fine, that is all. I think we were in hospital for one week.

HA: What do you wish for now?
009p: It is not in my hand [pause].

PWA’s coping is also reflected in being proactive. Finding alternative strategies for communication, such as using a mobile phone (as expressed by 0019p), is one way of being proactive.

0019p: With the mobile, for example I want [the patient showing how to use the mobile phone to type via speaking], for example "Abo Ahmed how are you" like this [inaudible segment].
HA: Yes, you can use the mobile apps so that you can type.

Being proactive is also observed in the desire to support and help other individuals who are experiencing the same medical condition, as reported by 0022p.

0022p: Even the normal people, seriously, I would like the people even if they get a stroke may God forbid, God willing, I would like to help the people who are, oh what I want to say .. God help me, the people who I would like to, God willing, the one who are in my situation and the one, sigh, I mean life [pause]
HA: You mean anyone, the ones who have stroke or anything else, you would like to try to help them with what you can.
0022p: Yes, and that is, not at all too much an asking, from God.

Proactivity is also evident in the attempt of the person with aphasia at self-dependence for improvement. 0022p's realisation that she needs to help herself and practise independently is an indication of accepting the situation and her willingness to improve with or without therapy.

0022p: I am trying to do the speech thing, the speech thing. I also try, God willing, the Quran, I will try reading, and I must, must, must try to help myself.
HA: You mean to be independent at home and do the exercises?
0022p: Yes.

In relation to family members, coping is reflected in their conviction and in depending on God while experiencing difficult circumstances in addition to also being proactive by seeking the treatment.

0018f: I swear, I mean myself, I stayed three months in Riyadh and we did exercises, I put all the devices at home, we do exercises, I went to ____ [travelled to a different country], I went to the _____[travelled to a different country], I mean I took, I mean there is no way or opportunity there I did not try, and the success is from God, praise to God Almighty, I am contented with what I have achieved so far, this is the human, something written for them to happen and being content. I see my situation is ok, God willing.

0012f: I mean before, he really had a brilliant future. At the accident time, he did an interview for a job, God, Glory to Him, did not want this to happen.

007f expressed that she wants her daughter to be less afraid from the consequences of stroke and aphasia by understanding that this was written by God.

007f: I want her to be convinced that this is from God, so not be afraid; did you get me? To be faithful.

Coping is also shown in the attitude adopted by family members. As reported by 0018f, patience was a means of overcoming the challenges that he faced after stroke occurred to his wife.

0018f: Being patient, I mean how I dealt with this issue. Sometimes I get upset from this issue, however I try to be patient in all situations.

The importance of patience was stressed by another family member. As 0028f expressed, families' patience while interacting with PWA and during the whole process is an important factor in rehabilitation.

0028f: I mean they should have patience when dealing with the other, the one who have the problem, and family should not become bored, and also they should try to help and make things easier.

The Venn diagram below (Figure 6.2) illustrates signs of coping that PWA and families exhibited with respect to the experience of stroke and aphasia.

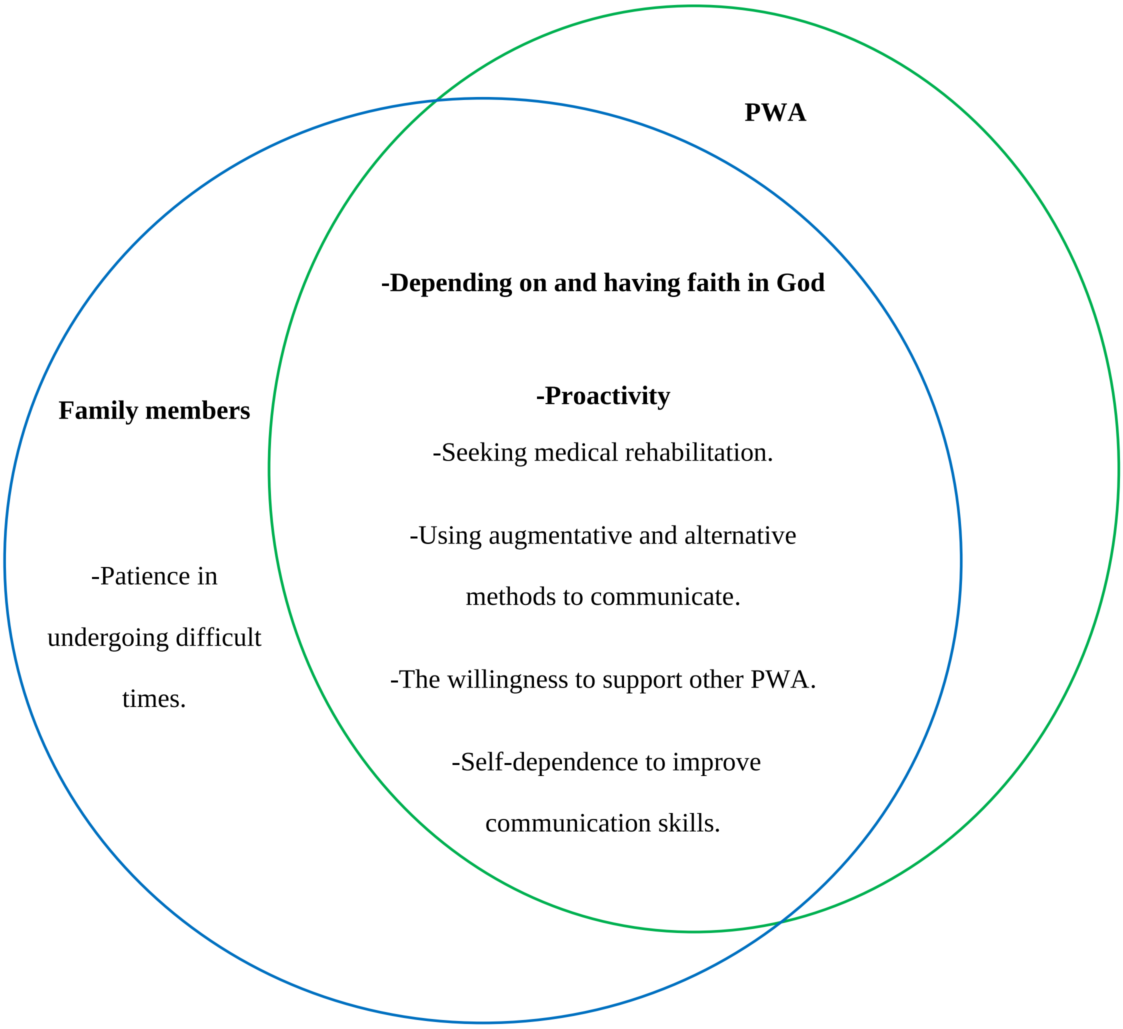


Figure 6.2 Participants' views on coping with stroke and aphasia

6.3.2 Sub-theme 2: Knowledge of stroke and aphasia among society

In this sub-theme, PWA and family members provide their views on the level of knowledge regarding stroke and aphasia in Saudi society. This sub-theme also presents participants' views on the need for awareness.

6.3.2.1 Insufficient knowledge

With regard to society’s level of awareness of stroke and aphasia, the majority of participants expressed that they have observed insufficient knowledge, which is reflected in different aspects including informal recommendations and communicating with PWA.

Most PWA reported that they encountered people who are not aware of stroke and aphasia. One participant with aphasia reported that the majority of people whom she met are aware.

0024p: Yes and I swear, all the one I met, they understand that you, that you had a stroke and that you I mean.
HA: All individuals you met understand?
0024p: Yes.

In contrast, 0019p and 0022p expressed that people in society lack proper awareness of stroke and aphasia.

0019p: There are some people ok, and there are others who do not understand it, and others [inaudible segment] what is it [inaudible segment] say what is aphasia.

HA: OK, if we said the society and people all need to know about stroke and aphasia?
0022p: Yes, let them know.
HA: OK, at the moment, they know or not ?
0022p: The people?
HA: Yes.
0022p: I swear they do not know.

For some individuals in society, signs and symptoms are not easily identified. Improper recommendations and a prolonged period of time before a medical diagnosis, which allows for severe signs to appear, could be consequences of not recognising symptoms of stroke when they occur, as in the extract below.

0019p: Yes? what happened to you? I swear I do not know, I swear I do not know [inaudible segment]. I could not tell you, he said, ‘go to a doctor, to someone who treats with cauterization.’
HA: Aha to do cauterization.
0019p: Whatever God wishes, I do not know what could cure it, I said, wow, it is something, I said ok, tomorrow, God willing [inaudible segment] we are at the moment playing cards [pause].

From the viewpoints of the family members, society also lacks awareness of stroke and aphasia. The family members believed that society’s insufficient awareness is reflected in how PWA are treated. PWA are sometimes ignored during communication or treated with sympathy, which might add psychosocial pressure upon them, as expressed by 0020f and 0023f.

0020f: Not even after the stroke, at the time of the stroke, I mean I went through a number of situations in which he wanted to speak, and all he got is ignorance. As a patient, such situation, sinks deep in his soul. You as a healthy person, if you said a word and someone ignored you, you could deal with it, but as a patient with a stroke, you could not deal with it as fluently as healthy person.

0023f: Sometimes I do not know how, I mean you have a lot of words you would like to say but you do not know how to say it, anyhow, the society perceptions that you are a weak person and someone must accompany you, and that society has done many things that made patients dependent.

0020f expressed that when she is outside with her husband and talks to people while he is silent, people question why a wife talks on behalf of her husband and the man is silent.

0020f: I speak on his behalf most of the time, and after that I see an amazement; a man is silent, especially after he became able to walk, and a woman speaks in his behalf.

007f expressed that her daughter feels pressured by people in the society constantly asking about her condition although they know what happened to her.

007f: This scares her, people in the society talks, we are ok with what God has given us, but they ask how she walks after stroke, how she speaks and how she writes; as if they are enquiring for something. I don't want to interpret their intentions, but they know and ask! This is the reason for her confusion which I want her get over it.

6.3.2.2 The need for awareness

009p expressed that accepting and being aware of stroke and aphasia is a necessity in society, which indicates that he encountered some challenges due to insufficient knowledge.

HA: All the people understand your situation, the stroke and the aphasia?
009p: Aphasia?
HA: Yes.
009p: They must understand it and with compulsion.
HA: This matter must be very important.
009p: This matter is very important

The majority of PWA reported that there is a need to spread awareness in society, which confirms their views on the observed lack of knowledge in society.

HA: That we aware society about stroke?
0027p: Yes.
HA: You think this is important?
0027p: Yes, yes.

HA: Society needs to know more about stroke and aphasia?
0011: Yes, yes.

Family members stressed the need to spread knowledge in society with regard to supporting the communication of PWA and how to interact with individuals who have communication difficulties in public places.

0020f: I mean to let them take their time and give them a space to speak until they understand them, because they are normal people, but because of the stroke they had the aphasia. When someone becomes upset and annoyed, his words do not come out and he feels suffocated, now imagine how is it for someone with aphasia who try to speak and knows he is right, but the one in front, thinks "what do you say".

0024f: The thing that is a barrier to my mother is that when we are not with her while she is going to an appointment, for example. Now if she went to a public office, the comprehensive rehabilitation office for example, she would not know how to explain to the officer there, and the officer would be shouting at her, the officer did not know that this individual is a special need person. I mean the people must become aware of how to deal with them, you see, she is a normal person but have communication difficulty, do you understand, that is it. I mean there were situations that made us upset a little bit.

The Venn diagram below (Figure 6.3) shows views of the three participant groups about knowledge of stroke and aphasia and need for awareness in the Saudi society.

6.3.3 Theme one summary

Within theme one, views of PWA and their family members were revealed in relation to the experience of stroke and aphasia in the Saudi context. PWA and their families expressed a sudden occurrence of stroke and confusion, challenge dealing with the new condition, coping signs, the level of awareness in Saudi society, and the need for social support.

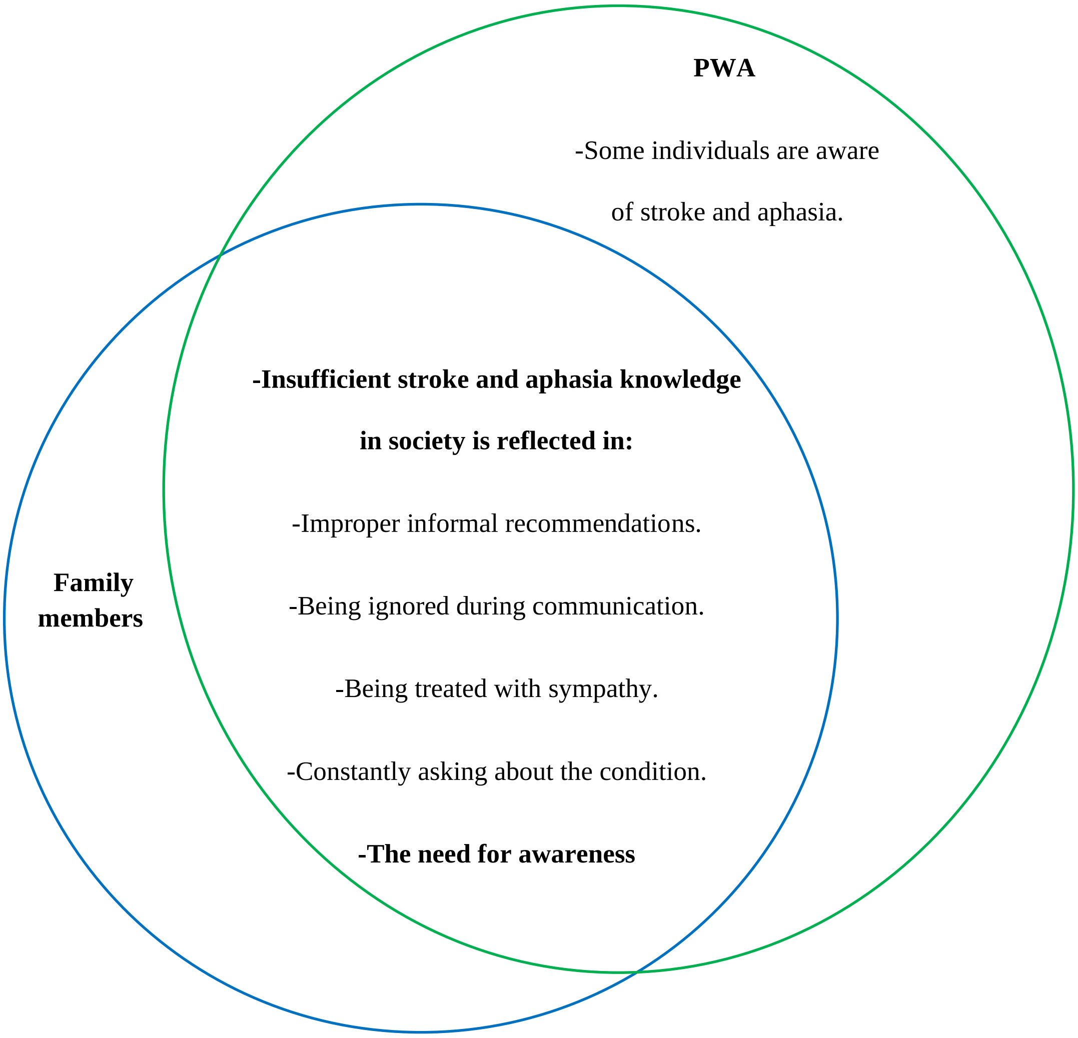


Figure 6.3 Participants' views on stroke and aphasia knowledge among the Saudi society

Theme one revealed that PWA and their family members constructed their experience as being sudden and confusing because symptoms were not recognised by them, and insufficient information was provided when being diagnosed. Challenges were encountered by family members in managing a new medical condition. The family members reported that the new situation was difficult, and that they faced communication challenges when interacting with their loved ones with aphasia. Coping was facilitated by religious faith and being proactive as

PWA and their family members expressed depending on God, seeking medical rehabilitation, using alternative methods of communication, willingness to support other PWA, and self-dependence to improve. The family members also reported being patient toward the situation and other family member including PWA.

Regarding the experience within the wider social context, most PWA and their families reported a lack of sufficient awareness among people in the society, which is reflected in different areas including improper informal recommendations, being ignored during communication, being treated with sympathy, and constantly asking about the condition of the person with aphasia which adds stress to them. PWA and their families viewed society awareness is needed to communicate properly with people with stroke and aphasia.

6.4 Theme two: The impact of stroke and aphasia

Theme two reveals how stroke and aphasia impacted different aspects in PWA's and their families' lives. Theme two presents the specific impact on PWA, on their families, and on the family dynamics as well. The details of theme two are as follows:

- Sub-theme 1: The impact on PWA.
  - Physical abilities and activities.
  - Communication skills.
  - Social participation.
  - Psychological well-being.
- Sub-theme 2: The impact on family members.
  - Social participation.
  - Psychological well-being.
- Sub-theme 3: Changes in family dynamics.

- The impact on familial relationships.
- Family support for PWA.

A detailed structure of theme two, which illustrates results and contributing views, is presented below in Figure 6.4.

6.4.1 Sub-theme 1: The impact on PWA

The data show that stroke and aphasia have an impact on PWA's physical abilities and activities, communication skills, social participation, and psychological well-being.

6.4.1.1 Physical abilities and activities

Stroke affected the mobility of PWA. 0019p expressed on loss of consciousness which he likened to death and the weakness that he experienced on the right side of the body as being dead on that side.

0019p: I went to doctor and told him while I was walking, suddenly my right leg stopped and I fell unconscious, as if dead.
HA: It has become weak?
0019p: Yes, yes, it has become as if dead, as if not there [inaudible segment]. The doctor wondered what happened, but I did not know, he said the doctor specialised in the, in the [pause].

The family members also expressed how stroke affected PWA's physical health. At the time of stroke, the condition affected the mobility of PWA. The inability to walk for some PWA was an impact that lasted for a period of time after the occurrence of stroke.

0010f: He has stayed for about a full month in ___ hospital. He could not speak or move any limbs in his body.

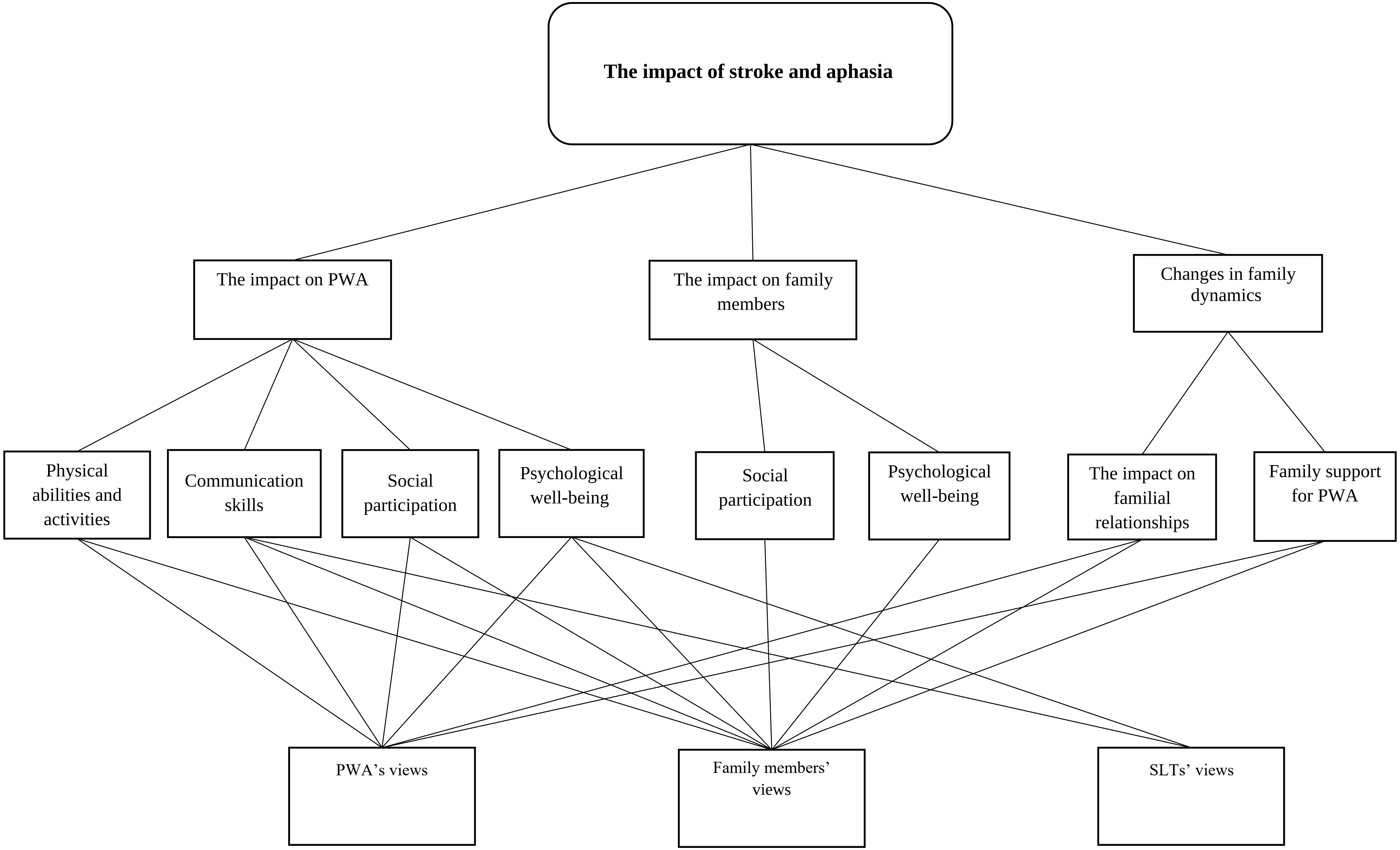


Figure 6.4 Theme two details and contributing views

007f: But now, thanks to God, she can walk; at first, she could not.

In relation to activities, stroke and aphasia affected PWA’s religious, daily and leisure activities, including praying, grocery shopping, and travelling, as viewed by PWA and their family members.

From the viewpoint of PWA the religious aspect is one of the affected areas after the occurrence of stroke. 0024p reported frustration in her inability to read the Quran. She described her inability to read the Quran and her loss of language as resembling an illiterate person who is in the process of learning everything from the beginning.

0024p: I told her I could not read the Quran or to think about it my mind, like an illiterate person who cannot read. This is what has happened in my brain; I cannot read or even speak.

Other daily activities including grocery shopping were difficult for PWA due to communication difficulties and fear of the inability to be understood by other people.

0024p: No, I do not even go to a grocery store. I am, glory to God, afraid he cannot understand me.

These challenges are observed by family members, as they reported the effect of stroke and aphasia on the religious activities of PWA.

0025f: She told us she had kept praying to God, but she had not known what to say apart from only repeating, ‘thanks to God’, ‘in the name of God’, do you know what I mean?

004f: Honestly, I have suggested, at the beginning of the week, that there should be more focus on the religious aspect, because he has forgotten the religious matters totally, be it the Quran verses or how to perform the prayer; so I told them to focus on the religious aspects a little bit.

Restrictions in practising pre-stroke preferred activities such as travelling were also affected.

0025f: Yes, she mainly, God has willed it, was active to the extent that she had already travelled and only told us the following day she was travelling.
HA: Wow.
0025f: She is living happily and very well [inaudible segment] [Laugh].
0025f: Do you know what I mean?
HA: God bless her.
0025f: That’s why she feels restricted now.

The Venn diagram below (Figure 6.5) illustrates the views of PWA and their families on the effect of stroke and aphasia on the physical abilities and activities of PWA.

6.4.1.2 Communication skills

The effect of stroke was reflected clearly in the difficulties of communication skills of PWA. For PWA, communication skills were severely impacted when stroke first happened; some used alternative methods to communicate (gesturing and mobile phone). Communication difficulties persisted and were present in expression, comprehension, reading, and writing.

PWA expressed that they experienced the inability to communicate not even with using gestures as reported in the extracts below.

HA: How could you communicate with people after you had recovered your consciousness after spending six days in hospital?
009p: I did not communicate with them at all.
HA: Not even with gesturing?
009p: I did not feel their existence [inaudible segment].

0024p: From first day I had a stroke, I did not gesture or anything. I could not order food or anything on my own; food was only served to me for two months.

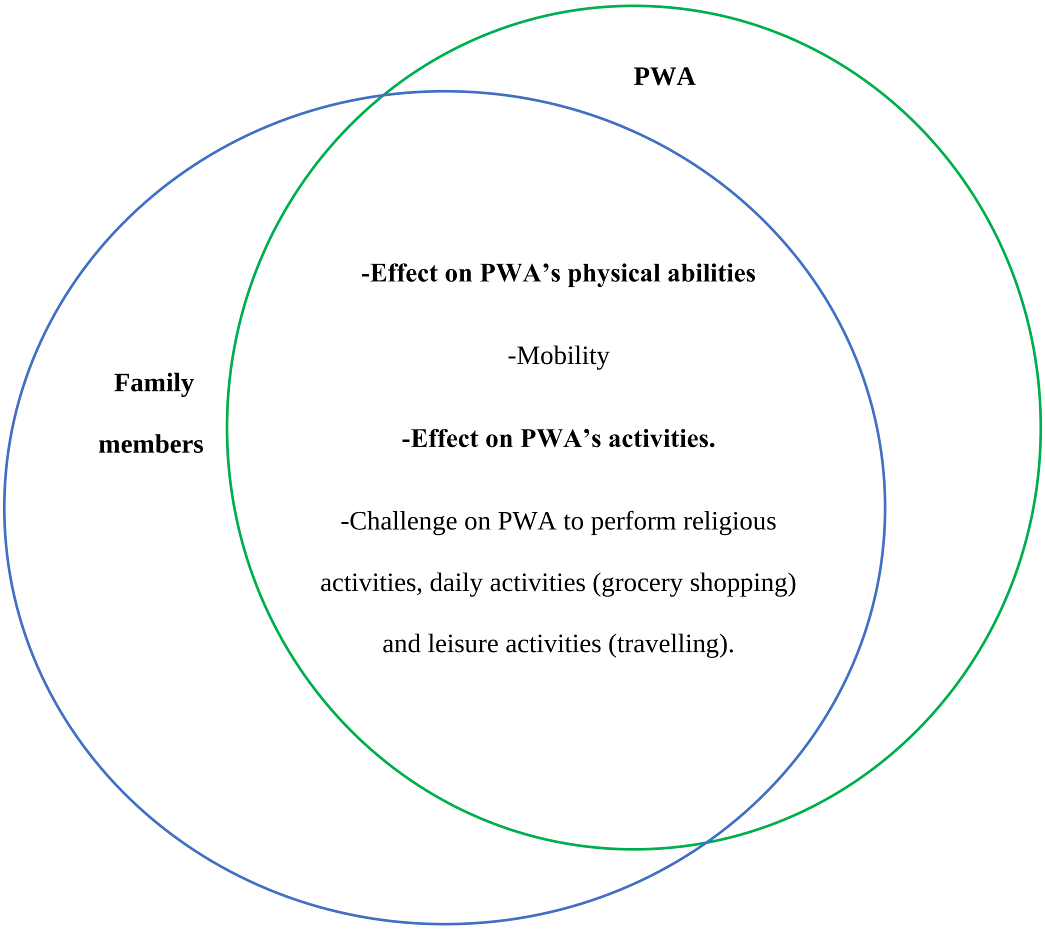


Figure 6.5 Participants' views on the effect of stroke and aphasia on the physical abilities and activities of PWA

0017p: I could not speak nor hear anything. Even if I could pick some words, I had no ability whatsoever to utter.

Using alternative method of communication (gestures) and making an effort to speak were attempts initiated by PWA to express themselves at the time of stroke.

006p: I would have liked to order food, but I could not except with gesturing.
HA: You could gesture?
006p: Yes.

0019p: Yes, you know that food choice is different for different patients. When I, for example, wanted to eat, I would say to them ahhh how ahhh how, 'I want ahh hamb hamburrr' I would have liked to tell them but I could not utter words [inaudible segment]

HA: Then you gestured?
0019p: Oh, yes that's it.

For PWA, communication difficulties persisted. 0019p expressed that language processing became more effortful, and that he needs time currently in which to process language, unlike pre-stroke.

HA: What about comprehending simple commands and information?
0019p: That is the problem, my brain is no longer fast as before, [inaudible segment] everything has to be one by one.
HA: Yes, matters should go little by little, a bit of information after the other.
0019p: Yes, exactly. If it was fast, I cannot.

PWA ranged in their views and how stroke affected their reading, writing, expression and reception. The majority of PWA reported that their reading skills fall between good and very good, while the majority reported that writing is affected and falls in the range of poor to very poor. With respect to expressing needs and understanding others, the majority of PWA viewed their expression to be between poor and very poor, while the majority viewed receptive skills to be good or very good. This reflects that the majority of participants with aphasia view their current expression skills (speaking or writing) to be more affected than their comprehension skills.

Family members also reported their views on the communication skills of PWA after the occurrence of stroke. Following stroke, they felt that PWA varied in their communication abilities, as some were unable to communicate using any means, whereas others used alternative communication methods (gestures and mobile phone).

0010f: At first, he could not utter a word, but, now as you see, he can little by little speak intelligible speech.

004f reported that gesturing was a mean to communicate with his father, and that his father used a mobile phone to find the name of the intended person.

004f: No, he, for example, opens the names list and searches for a name and refers to it.
HA: Can he for example order anything he wants with the help of its image?
004f: No, he still cannot do it.

004f: We used to gesture at first stages; we gesture and he gestures as there were no speech and language therapists at the general hospital in the other building to explain matters to us.

The family members also expressed that communication difficulties persisted and were observed in the challenge that PWA face in expressing their needs and thoughts by speaking.

0030f: The same thing now, he knows what he wants to say but he cannot express it, in respect to reading, sometimes, the alphabets, somewhat I mean, God help him, but praise to God, we got used to it now, we and him, little by little, praise to God.

0018f: She even keeps repeating some sentences and words; she is uttering a few repetitive expressions.

Similar to PWA and family members, SLTs expressed that communication difficulties were severe at early stages when PWA first came to speech and language therapy. 005s reported that an alternative method of communication (gesturing) was used by the person with aphasia to communicate.

008s: At the beginning, she was severe aphasic non-fluent and nonverbal.

005s: The patient, at the beginning, his speech was difficult, but at the beginning he was trying to express to us that he wants to speak and get back to how he was before, this is one of the points that he was trying to communicate to us with words and gestures.

SLTs reported that different aspects of communication were impacted. Expressive and receptive difficulties, in addition to apraxia, were the major observed areas.

005s: At first, stroke and aphasia were so severe that his cognitive and language abilities were badly affected; both comprehension and expression.

0015s: He had more problems in expressing his needs. In other words, he had difficulty in connected and conversational speech. However, he can still communicate his wants and needs and naming things.

0026s: She had severe aphasia severe apraxia. At first, the only thing she answered was her name. Other than that, she had no verbal output.

Due to such difficulties in communication abilities, some individuals might develop strategies with which to cope with their inability to express as they used to, such as discontinuing a conversation when facing word-finding difficulty. The SLT in the following extract expressed what was said by 0019p, who receives speech and language therapy with her.

0015s: ‘I was searching for it, and when it does not come up, I would leave it and stop the conversation’.

The Venn diagram below (Figure 6.6) illustrates the views participant groups on the effect of stroke and aphasia on communication skills of PWA.

6.4.1.3 Social participation

Stroke and aphasia affected the social aspect of PWA’ lives. The restriction in social participation is evident in PWA’s social withdrawal and the challenges faced by PWA in terms of pursuing career goals.

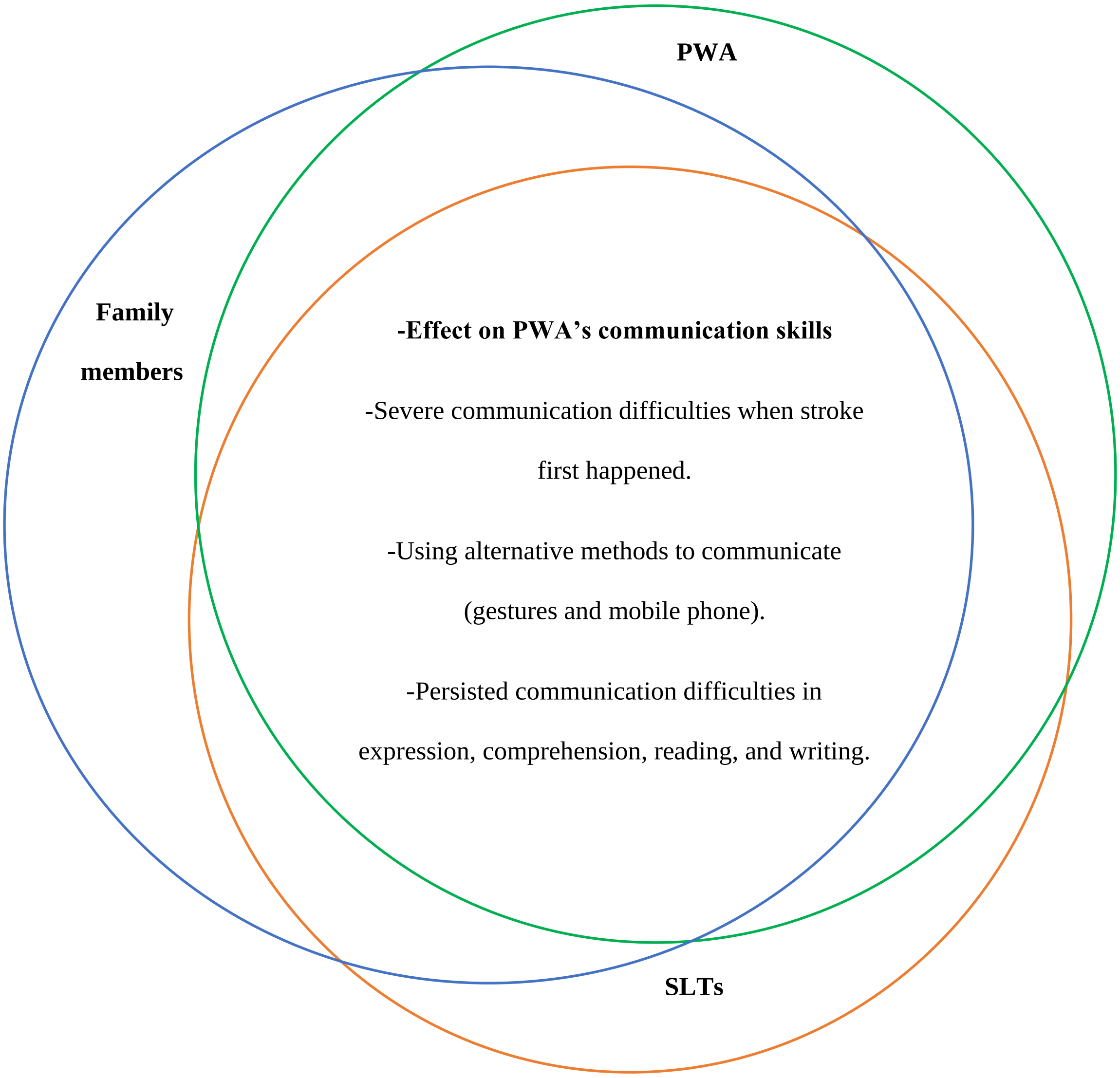


Figure 6.6 Participants' views on the effect of stroke and aphasia on communication skills of PWA

0024p reported a lack of confidence in approaching people after experiencing stroke because of her communication difficulties, although she was a social person before experiencing the medical condition.

HA: Do you initiate conversations with strangers?
0024p: No, I don't have the courage in the gym [inaudible segment].

Stroke and aphasia prevented 0019p from returning to his previous job, thus leaving him unable to provide for his family. For him, being healthy physically is a priority in returning to work and providing for his own family.

0019p: I'd like to, God willing, I want my hand to be as used to.
HA: Yes, I know what you are getting at.
0019p: I mean maybe I tell my daughters that such is black and such is such [inaudible segment]. 'Say its name; no, do it once more', got it?
HA: So, do you find that strengthening your body is your priority?
0019p: Yea, sure. It is necessary for the sake of my household.

From the viewpoint of family members, stroke and aphasia affect the interaction of PWA in society. The impact of language difficulties is shown in the increased chances of misunderstanding during communication, as in the following situations. 0010f explains the challenge his father encountered when he attempted to talk nicely to people, but he was misunderstood, so they tried to get the rights back by approaching senior people in the tribe.

0010f: We live in a tribe which has traditions of rights and duties which cause worries and stresses. Here, there are people who do not know that my father has aphasia or speech problems. We may come across some of them in the street who may blame us, out of misunderstanding; at the same time my father wants, mainly, to praise them. Then, they may demand their rights and make recourse to many Sheikhs of the tribe. No, it is not worth it. I am ready to redress his wrong, but he makes a big issue of nothing and calls people to see he is wronged.

0025f: At first, she did not reply correctly. If for, example, someone greeted her with 'peace upon you', she would reply as 'I am fine', do you know what I mean?

Over time, PWA started to feel less confident, withdraw, and decrease their interaction with their surroundings for fear of misunderstanding as in the following extracts.

0025f: You feel that she is ashamed that strangers may do not understand her or think that she is impaired. No, it should be normal. Got it?

0020f: He was an active sociable man. He was not, God gives him recovery, a stay-at-home kind of person. Therefore, when he had a stroke, he missed family and friends which was a shock in itself.

From the viewpoint of family members, stroke impacted also upon the occupational aspect of PWA's lives. Since experiencing stroke, PWA can lose the opportunity to obtain a job that they are pursuing due to the physical and communication challenges as reported by 0012f.

0012f: I mean before, he really had a brilliant future. At the accident time, he did an interview for a job, God, Glory to Him, did not want this to happen.

The Venn diagram below (Figure 6.7) illustrates the views of PWA and their family members on the effect of stroke and aphasia on the social participation of PWA.

6.4.1.4 Psychological well-being

Stroke and aphasia have an impact on the psychological well-being of PWA. The sudden life changes and the challenges encountered by PWA added negative feelings to PWA.

PWA expressed experiencing different feelings of being a burden, missing life pre-stroke, anger, and being overwhelmed. The emotions experienced by 003p were new and painful to him when he experienced stroke.

HA: What have you wished for most when you had stroke?
003p: I have wished to get better. There were things I experienced for the first time in my life.
HA: First time to experience.
003p: It was difficult.

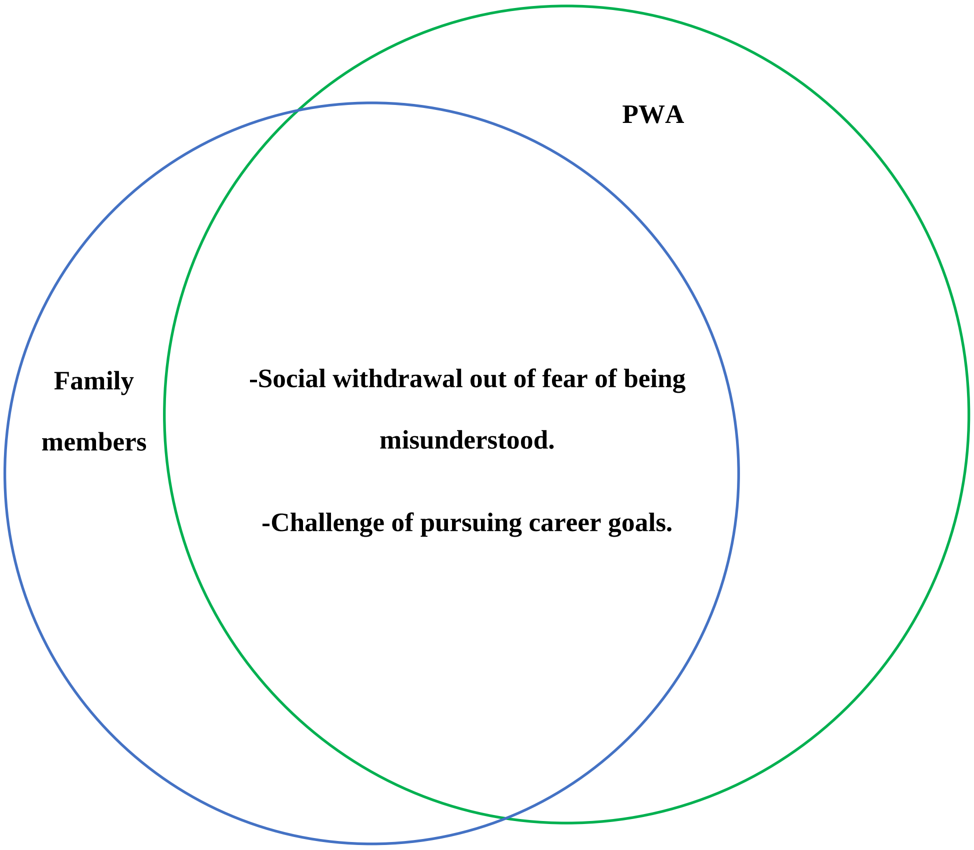


Figure 6.7 Participants' views the effect of stroke and aphasia on the social participation of PWA

Stroke and its physical impact forced 0019p to take a break from working; thus, he was unable to provide for his family. This situation exerted pressure upon him and led him to feel like a burden on his wife.

0019p: I wish to go back to work.
HA: You wish to go back to work.
0019p: There is no god but God [pause]. I want to go back to work for the sake of my children, I want to go back to work because my wife is exhausted.

The psychological impact of stroke was in the form of overwhelming feelings for 0022p and 006p. The overwhelming feeling experienced by 006p was reflected in her loss of appetite and the desire to leave the hospital when she first experienced stroke.

006p: I do not know; my family was getting me food, but I had no appetite. They made me eat. All I wished for was to get out of the hospital.

The overwhelming feeling of 0022p was evident during the interview, as she cried while remembering the event of her waking up in the hospital. She reflected confusion in respect of perceiving that everything was normal, albeit in a hospital and enable to communicate.

0022p: No, I was in ___ hospital. I do not even know. When I was ill, by the way there was a thing when I was ill [Pause]; I don't know as if I was normal even though there was no speech. Thanks to God any way, but as if I was normal [crying]

The psychological impact on 009p was reflected in his feelings of anger towards the stroke, as he expressed during the interview:

009p: God damns stroke.

Furthermore, participant 009p had an emotional moment during the interview with respect to how he was missing his camels, which reflected his emotions regarding missing his life pre-stroke. Since 009p was receiving aphasia rehabilitation services in Riyadh (central region of Saudi Arabia), he was not able to be at his home city near his camels while receiving rehabilitation.

HA: How many camels do you have?
009p: Seventy.
HA: Seventy! Here or in ______ (a city in Saudi Arabia)?
009p: In ______ (a city in Saudi Arabia). You made me [inaudible segment] [Emotional]

From the viewpoint of family members, the psychological effect of stroke and aphasia on PWA is reflected in frustration and feeling overwhelmed. The family members viewed the frustration of PWA as a main consequence of the inability to convey a message.

004f: With passing of days, he began to refer to most of things using gestures. Sometimes he got nervous as he couldn't communicate things he wanted. Then, some face expressions began to appear as he began to touch his mouth conveying that there was something he liked to express but he could not. At that time, it became clear to us he had an Aphasia.

0025f: She was nervous and easily got irritated to the extent that you might feel she was completely fed up.

0028f: When she is fluent, she feels psychologically good, but when she cannot express herself, she feels nervous and gets irritated.

0023f: Because of the difficulty of speaking, sometimes she cries, and other times she gets emotional and cannot express.

From the viewpoint of SLTs, stroke and aphasia have an impact on PWA's psychological state because of their communication skills. SLTs reported that they observed low self-esteem, shyness, and signs of depression within PWA.

0015s: When 009p first started therapy, he had low self-esteem because he felt that he completely lost the ability speak.

008s: At first, I provided a program to the patient's mother on how to communicate with the patient as she (006p) was shy and depressed. She did not like to talk especially to her family male members.

The Venn diagram below (Figure 6.8) illustrates the views of participant groups on the effect of stroke and aphasia on the psychological well-being of PWA.

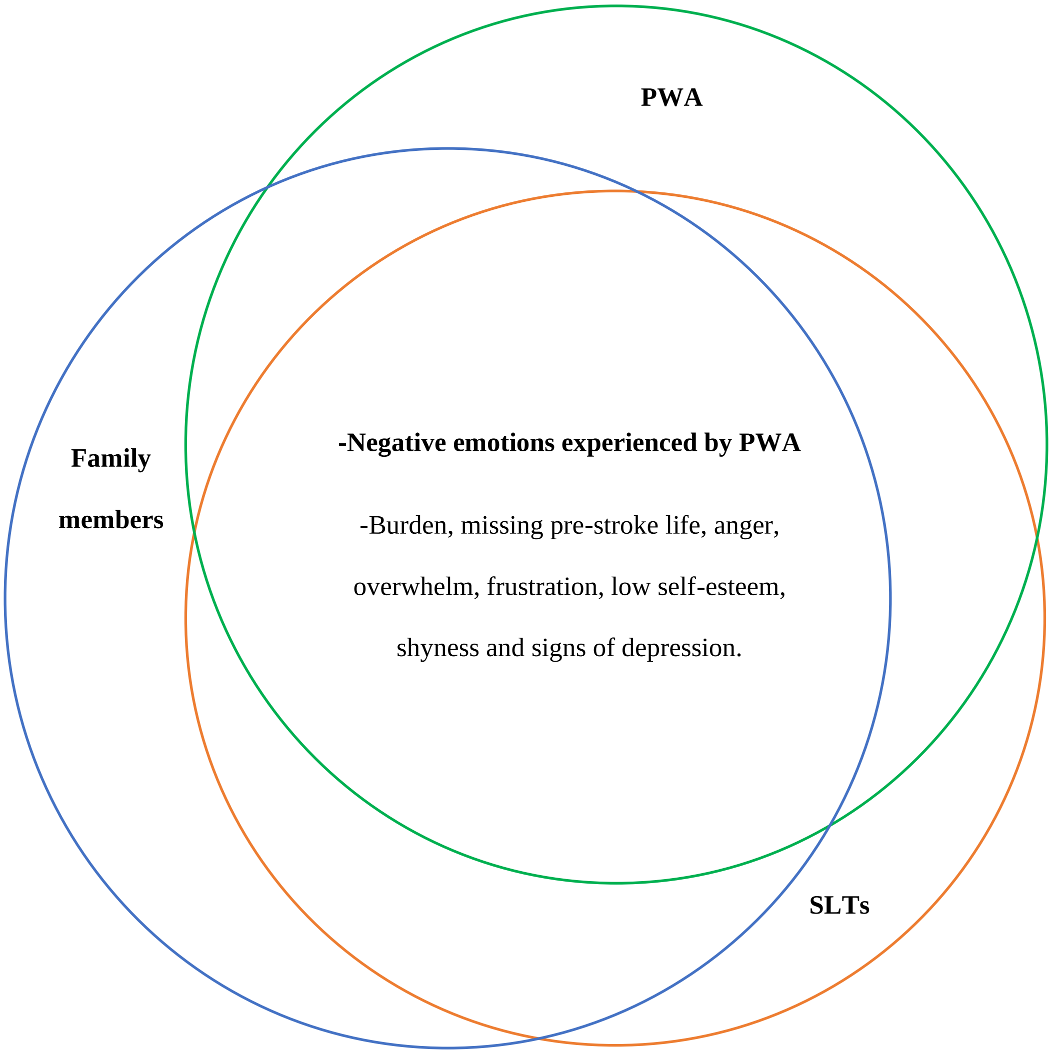


Figure 6.8 Participants' views on the effect of stroke and aphasia on the psychological well-being of PWA

6.4.2 Sub-theme 2: The impact on family members

The data show that stroke and aphasia have also an impact on the family members. The social participation and the psychological well-being aspects of family members' lives are impacted by stroke and aphasia.

6.4.2.1 Social participation

Stroke and aphasia affected the occupational aspect of family members as well. A daughter, who is the caregiver of a participant with aphasia, revealed that her desire to pursue a job and further education has also been affected since stroke, as she is the only caregiver upon whom her mother depends.

0023f: What I hope for myself is to be able finish what I have begun. I have graduated from university and at the time I was searching for a job and taking courses, my mother had a stroke. My life has stopped; I am trying my best to help myself overcoming difficulties. I am the only daughter in my family, and we don't have a housekeeper. Even when I tell her about this, she would not want someone to work full time.

0023f: I wish I would be independent and rely on myself. I am tormented much when I see my university learning and the many courses have gone with the wind. There is much power I want to employ but, at the same time, I cannot do anything when my mind is fully busy with her.

6.4.2.2 Psychological well-being

While stroke and aphasia had a clear impact on PWA, the condition also affected their family members from an emotional standpoint. The effect is shown in the negative influence on the whole family due to related feelings. Feelings varied across family members, including feelings of being overwhelmed, worry, default, apathy, guilt, and sympathy.

The daughters of two PWA experienced feelings that reflected their responsibilities towards their own mothers. 0023f experienced feelings of being overwhelmed because of the stress of her being the only daughter in the family; therefore, she feels responsible for always attending to her mother's needs.

0023f: Yes, I am compelled as there is no other one can do it. I am trying to tell her not to stop trying even if I wasn't there. Sometimes she tries to read, and if she cannot, she calls me and ask me to read it. She says that the letters are small; but sometime they are big! Sometimes I cannot do my best because all responsibilities are on me.

This feeling of being overwhelmed, as experienced by 0023f, added a level of pressure upon her, as she experienced feelings of default and then apathy.

0023f: I sometimes cannot do my best, but this is not in my hands.

0023f: I noticed apathy after she got ill.
HA: did you feel that form her side?
0023f: It is my responsibility as well as I do not dedicate all my time.

This emotional experience of being the only caregiver to a person with aphasia put 0023f in a position of being at a loss between achieving her personal goals and supporting her mother.

0023f: There are many things I want to do, but I cannot as I am worried about her.

The daughter of another participant with aphasia experienced feelings of constant worry about her mother being independent again post-stroke.

0025f: I would like her to go back as she was before stroke, but not to come as she used to. Believe me; we are very concerned about her. By God, we are deeply concerned. I think a lot about her so that I am thinking what would become of her if she relapsed in Riyadh city and she was alone. Got it?

0018f (who is the husband of a participant with aphasia) and 0012 (who is the father of another participant) experienced feelings related to sympathy. 0018f's sympathy is reflected in his realisation that the communication abilities of his wife are not the same anymore, whereby causing him to experience exhaustion and painful feelings.

0018f: I mean, in fact, it is very tiring feeling [inaudible segment] and painful at the same time. Imagine you are waiting for an answer from someone who is searching for the answer, words and utterances. It is somehow sympathetic.

In addition to feelings of sympathy, 0012f, who is the father of a participant with aphasia, experienced the burden of guilt, as he had a small conflict with his son prior to a car accident and then stroke.

0012f: Yes, it is extremely sympathetic; it also arouses many things, and it is remorseful. No one can imagine it; like why you had shouted at your son, then he left home indignant and made an accident. People misunderstand; it did not happen this way. That's why it had a negative effect on family. [Inaudible segment]

6.4.3 Sub-theme 3: Changes in family dynamics

The data show that stroke and aphasia changes family dynamics. Familial relationships are impacted by the condition. Changes in family dynamics is reflected also in the support received by PWA from their family members.

6.4.3.1 The impact on familial relationships

Stroke and aphasia affected the marital relationship negatively, as well as enhancing family bonding positively.

The marital relationship is one of the aspects affected within the family dynamic. As expressed by a participant with aphasia, 0019p prioritises enhancing the communication between himself and his wife, as it is an affected area post-stroke.

HA: Would you like your friends understand you when you talk?
0019p: Yes, but my wife is the most important to me.

The husband of a participant with aphasia expressed frustration regarding the same issue of the marital relationship. 0018f expressed frustration with regard to the changes in the quality of emotional exchanges between him and his wife due to the communication difficulties.

0018f: She is trying, but notice that, even in her emotions, she is repeating the same sentences and expressions; it is hard to instil feelings in someone, are you getting at what I mean?

0018f described the expression of his wife, who is a participant with aphasia, as resembling a recorder that repeats the same tape continuously, and as a doll that repeats the same sentences.

0018f: I mean I can interact with my conversationalist who can express him/her self freely, but the problem is when the same pattern of speech is repeated like a recorder.

0018f: For example, why don't we have a plan to restore feelings and emotions. I mean sometimes, do you know how the doll repeats expressions over and over to the extent that you don't notice it anymore? This is how she is, repeating same expressions and words, I mean there is a lack in her vocabulary.

Although stroke and aphasia have a negative impact on families, as reported above, some positive influence is evident in the data. Stroke and aphasia enhanced family bonding, as reported by family members in the extracts below. Such positive interaction between family members after the occurrence of stroke could be attributed to the love and support given to a vulnerable person who was once completely independent and giving to the family.

0020f: The kids tried to watch the youngest and imitate him. Though their father was strict with them, he is now trying to endear to them. Thanks to God the kids didn't share negative feelings.

0025f: She is getting better, and she is depending on us. I want her to depend on us and to tell us her needs. I like it this way; it allowed us to become closer. She alone was doing all household things which was wrong

6.4.3.2 Family support for PWA

In addition to positive and negative impact on familial relationships, the changes in family dynamics is reflected in the support given by family members to the stroke survivor with aphasia although data show that family members' lives are also affected after stroke. In relation to the negative effects that stroke and aphasia impose in PWA, family members reported that they provide emotional support to PWA and encourage PWA to practice some activities and increase social participation.

Families expressed that they accompanied their loved ones with aphasia most of the time so as to provide support and care when they receive treatments. PWA were accompanied during hospitalisation and when traveling to receive rehabilitation services as in the extracts below.

007f: Her sisters accompanied her when she was admitted as inpatient at the beginning, but on the day she came here to rehabilitation, I came with her; sharing her everything.

0030f: I was always there with him. I have stayed with him in hospital although they were very reluctant as he was staying in a shared room. But I did not want to leave him alone lest he could regain his speech power and find none of his family members beside him.

HA: I mean were you with him in all his travels?
0010f: Yes, we were.
HA: And have you attended sessions with him?
0010f: Yes, we have.

Family members expressed providing emotional support to their loved ones with aphasia and make an effort to motivate them and elevate their spirit while undergoing such a difficult time.

0023f: I was amazed that she thought that people who had stroke and aphasia, their lives have come to an end. I try sometimes to give her a motivation and make her concentrate in something good for her. She sometimes responds to me and at other times she does not. I am close to her, so I cannot affect her much.

007f: I want her to stop that; I want her to know that her family must always be with her and not be afraid of them so that she would not be afraid of other people, right or not?

007f: She was engaged and she argued with her fiancé, so they cut off their relationship. I do not want her to be convinced that he has left her out of her illness. I want her to be strong enough to live her life naturally.

In addition to emotional support, families encouraged PWA to practise some activities and participate in society. Family members motivate PWA to travel abroad, find a job and initiate communication with co-workers.

0025f: For example, once she was discharged and had recovered from the stroke, I exerted great efforts so that she could recreate herself by travelling outside Saudi Arabia. She has already returned from Australia, and she was walking there a lot. There, she has changed a lot, and her psychological state got better, so I always think about her recreating herself.

007f: She tells that she wants nothing for the time being and that she would find herself a job later. I want her to work so as not to be controlled by depression and not to be preoccupied much with black thoughts that she could never speak or work or have a partner.

0018f: We at home, and even her friends; I was driving her friends to speak more and more with her. I wanted her to take courage and take the initiative to speak.

0025f reported helping their mother to practice religious activities post stroke as she encountered challenges to pray.

0025f: At first, she prayed with the piece of paper in her hand, but then praise be to God, the family members have had big role. I mean imagine if someone is normal, for example, and is learning a new language, if there are no exercises, the person wouldn't learn the new language. Therefore, this is what we do with her; she takes the speech and language therapy session, and then we apply at home.

0025f: God willing, she can read now, but she tells me she does not know what to say in her prayers apart from the words 'thanks to God, you know, and 'praise'; That paper he did for you with 'in the name of God' written on it?
0024p: Yes
0025f: My brother has written on pieces of paper 'glory to God' 'thanks to God' 'no god but God' and 'there is no might or power except with God'.

Another family member also reported revising Quran with his father as part of daily exercises since this area is affected after stroke.

004f: Of course, he is still an inpatient in the hospital, so whoever of us was with him, he would revise the Quran and the speech and language session he received in the morning.

Families' support is also evident in the data of PWA. They expressed that their families were accompanying and visiting them in order to provide support when they experienced stroke and were vulnerable.

0024p: When I had stroke, I did not know because I was unconscious. They told me that my family had been talking to me. Thanks to God, they kept visiting me in hospital every day. In the evening, they were accompanying me in the hospital garden. I have kept improving day by day thanks to God, for two years now.

HA: Ok, did physicians afterwards explain the reasons to you?
0017p: To my husband.
HA: Your husband used to listen to doctors and then told you?
0017p: Yes.

Family's support is appreciated by PWA. In the extracts below, PWA reported that the support given by their families plays a role in their progress in aphasia therapy.

HA: What would help you to further improve your communication skills?
0029p: The family.
HA: The family.
0029p: They should be patient.

HA: Ok, praise be to God, would you like to add anything that you feel help you more, or help those with aphasia?
0024p: Maybe the therapy and support from the family and from others if any.

When the support is not provided as expected, PWA experience some hurtful feelings. 0019p expressed that he needed his brothers' support, but that they are not always with him. He is receiving support from his wife and mother. Since his wife is assuming all responsibilities, he experiences some hurtful feelings because his brothers are not involved as he needs.

0019p: My brothers and I; they did their best, but everyone has his own home and work. I mean I am your brother; try to see what I need. If I need hospital, if my wife needs something, if there is other thing. My wife is the one holding all responsibilities [inaudible segment]
HA: Did you get a little annoyed?
0019p: Yes, one wonders how one's brothers, got it?
HA: Yes, got it.

0019p: Yes, I mean a person needs his family and brothers. It is not the wife that has to carry out everything; brothers have to check their ill brother from now and then. Brother should call his brother by phone [inaudible segment] to know if he is in good health [inaudible segment] but, I did not hear from them for a long time [inaudible segment].

6.4.4 Theme two summary

As in any medical condition, and as emerged from all participant data, stroke and aphasia have a direct impact on PWA and their family members. The physical abilities of PWA were affected, as expressed by all participant groups. Daily activities including religious activities and shopping become hard post-stroke for PWA.

All participant groups reported communication difficulties as being a major area affected in the abilities of PWA. This shared view could be attributed to the fact that changes in expression and comprehension abilities post-stroke are usually noticed and easily detected. This also could be attributed to the nature of the study, as the focus is mainly upon communication.

The psychological and social aspects were also affected areas in the lives of both PWA and families. Stroke and aphasia have a clear shared impact on both PWA and their family members, as reflected in their psychological state and their social and familial lives. This could indicate that PWA's and families' lives are rebuilt around stroke. Both PWA and their families experienced negative feelings including feelings of being overwhelmed, in addition to challenges in achieving career goals.

Changes in family dynamics are also caused by stroke and aphasia. Challenges in marital life were reported by some participants, whereas some reported positive impact on family bonding. Moreover, family members reported providing their support for PWA in areas that were affected in their lives. Family members provided emotional support, facilitated activities including religious ones, and also encouraged social participation of PWA.

6.5 Theme three: Identifying therapeutic goals

Theme three presents SLTs' views on how they identify aphasia therapeutic goals in clinical practice. The theme presents how SLTs identify goals to be set in the therapy plan of PWA as they take into consideration the individuality of the case and achievability of goals. Theme three also presents SLTs views on how PWA and their families are involved in aphasia therapy in relation to therapeutic goals. The details of theme three are as follows:

- Sub-theme 1: Individuality of the case.
- PWA's abilities.
- Functional needs.
- Sub-theme 2: Goal achievability.
- Small steps and to achieve goals.
- Realistic steps.
- Sub-theme 3: Involving PWA and their family members.
- Discussions to incorporate realistic goals.
- Recognising PWA's and their families' goals.

A detailed structure of theme three, which illustrates results and contributing views, is presented below in Figure 6.9.

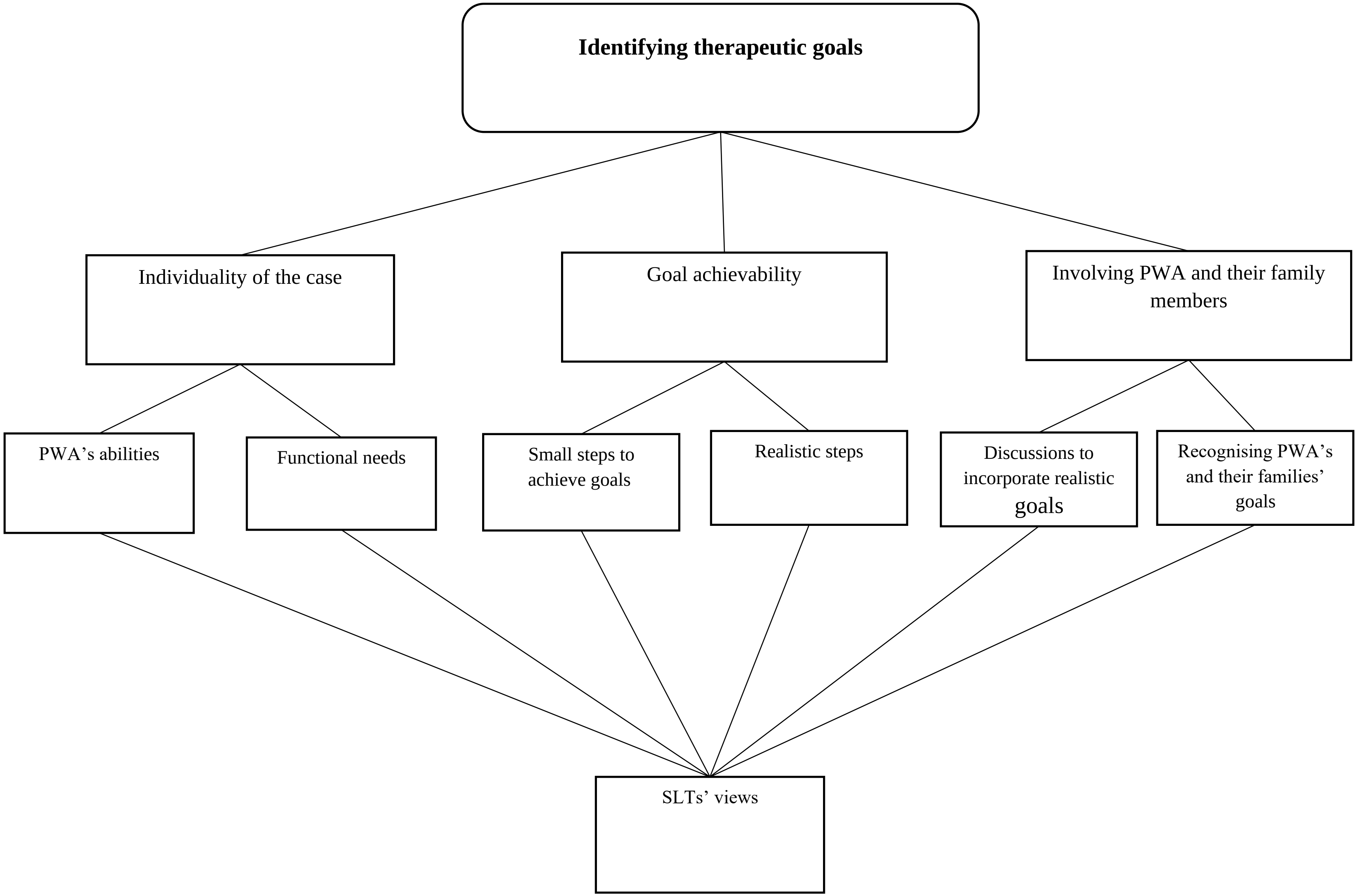


Figure 6.9 Theme three details and contributing views

6.5.1 Sub-theme 1: Individuality of the case

The data show that SLTs take into consideration the individuality of PWA's cases when setting therapeutic goals in aphasia therapy. SLTs expressed identifying therapeutic goals based on PWA's individual abilities and functional needs.

6.5.1.1 PWA's abilities

SLTs reported conducting informal assessments as a pre-step to goal-setting, wherein the abilities of PWA are investigated in detail so as to understand strengths, weaknesses, severity, and the appropriate and effective prompts to facilitate language processing. Therefore, areas of weakness are a target of improvement in therapy as reported in the following extracts.

0016s: Emm, the first thing, when he came in, we did a screening, I mean language screening, on the basis of it we got the basic diagnosis. So, we have to do, what is called, the full informal language assessment, here at this place, so that we can see in details his case, and on the basis of the full assessment results, we specify the goals for the patient, what exactly his level in each area.

0021s: After the assessment, after assessing the patient, I identified goals, on the basis of his weakness I mean. After that, it was discussed with the patient as well as the whole medical team.

0021s: After the assessment, we start to explain our goals to the patient and the family, after that we explain the goals to the medical team, the doctor and the rehabilitation therapists, be it physiotherapist or occupational therapist, psychologist; so we explain and discuss the goals with them. Sometimes, for example, we need to explain to the therapists how they should deal with the patient with aphasia, how they give the command, what is the easiest way for the patient to understand. Sometimes we explain to them the method of communications, if there is an alternative method, AAC, we explain it to the therapists, after that we start the therapy.

0031s: The first thing we did a full assessment for him, after that, we chose for him the integral stimulation because it is the best therapy for apraxia; we were giving more attention to the apraxia than the aphasia; I discussed with my supervisor the choice of what the best therapy for him; we started with him with the integral stimulation therapy, and when we saw improvement with him we continued with it.

6.5.1.2 Functional needs

Functional needs are considered as many SLTs reported. Cases are different in their characteristics and needs; thus, goals are individualised to each person as reported by SLTs in the extracts below.

0015s: This comes with experience, it is, of course, with every patient is different, because it depends on his case and also the presence of psychological behavioural issues. Also, whether cognitive impairments are present and whether receptive part is affected or not, so every patient has different severity.

0026s: Ok, starting three years ago, I have been providing aphasia therapy; different diagnosis and different severity. Emm, I mean, somewhat every patient's goal is different from another patient.

0026s: Emm, the goal is something, emm, something realistic, and I truly can identify it in a specific period of time. I feel, this is what it is, and also related to the patient.

Considering functional goals is also reflected in identifying goals that are related to PWA's basic and daily activities. 0015s, 008s, and 005s reported that they set therapeutic goals which are functional and tailored to the lives and needs of PWA.

008s: I determine a certain task that enables the achievement of a certain purpose, compatible with the patient's needs and achieves the thing that I want to reach at the end, equally the same, whether communication or speech and writing improvements.

0015s: After doing the assessment as I said, it depends on the severity, for example if my goals were ‘how to communicate effectively in his daily living’ and ‘communicate his wants and needs’ these are basic goals. If the case was very severe, these will be the goals only. If for example the case was like Mr.___ at the conversational or connected speech level, of course, I improve his conversation; I won’t focus on communicating his wants and needs; I will improve verbal expression and word retrieval.

005s: And we try to choose functional goals that help him on his daily living life, whether he was a young or an old-age person, and what the requirements are for his daily life, that he needs to fulfil, we try to identify goals on those bases.

005s: So, we try to see what the functional things, that this person needs, and then we identify the goals on the basis of these needs.

In the view of 0015s, identifying functional therapeutic goals also means that goals should lead to better communication in patients’ environment and with different partners.

0015s: With aphasia, or in general, it is that he can communicate his wants and needs in his daily living. I mean to be able to communicate with different partners, because some of the patients communicate, strictly only, with their families; and when this patient is brought into a different situation, he cannot communicate. We try to make him functional; it is not necessary we get him back to where he was, but functional, he can communicate his wants and needs with different partners, different environment.

Setting functional goals is reported to be achieved by considering the functional needs of PWA at every stage of therapy, and working on related goals as expressed by 008s.

008s: At the beginning, the goals are basic and functional. The patient leaves, especially if it is an inpatient, with a communication method, whether verbal or non-verbal. The step after that, is the functional goals, we make them more natural, in conversation and daily life activities and more complex level. Then we move on to the other goals, especially if the patient is a working or working, such that, as much as possible, we get him back to his previous job or education. We start, specifically, to reach this goal, whether academic goal or medical goal; at the same time, we follow the difficulties that the patient faces when he gets back to his work or education and we work on these.

005s reported that functional goals should enable PWA to practise activities in which they are interested or return to practising some pre-stroke activities.

005s: The goal we set, the most important thing is that we set activities that leads to that goal, and the goals must be things that treat the patient functionally for his daily life. I mean for example, an accountant, it would be possible to get him back to be able to do his basic accounting tasks, another example, someone works at a central calling centre, it would be possible to get him back to answer the phone. I mean we reach a functional goal.

Designing the therapy session and choosing activities also reflect how SLTs take into consideration the needs of PWA. SLTs in the extracts below reported using functional tasks and words in training, as well as considering the age of PWA when choosing activities with which to gain their interest.

0016s: In the goals of following commands, we can use body parts if I want to target body part identification and following commands at the same time. I use body part for following one step command; for example, ‘point to your eyes’, or ‘raise your hand’. Sometimes, not sometimes; we should do functional following commands. The functional things are the usual things like ‘give me water and turn the TV off; functional daily activity commands.

0031s: We find what the phrases that he uses daily are and we work on them; because his case is not only aphasia but apraxia too, the sentence comes out sometimes correct and sometimes not; sometimes the word comes out correct and sometimes not. So now, the goal that we are working on is on functional phrases.

0016s: This patient is 24 years old, so we must make the session fun and a bit functional, and in things in his daily life.

0015s and 0016s expressed that family members’ input in therapy sessions helps them to identify functional words for PWA.

0015s: One patient, for example, loves telling about camels, he loves telling about what he was doing when he was at the desert. I cannot communicate with him about such things of which I am not experienced. Therefore, one of his children can interfere driving him to narrate what he was doing and saying at some camp, for example.

0016s: Of course, they help me with the functional words that he needs, for example, at the session time if they understand the technique that I want teach him and when I give him a word, the family or parents can interfere to give feedback in many ways like training him on the word “mobile” since he always uses it. They were helping me in the session

6.5.2 Sub-theme 2: Goal achievability

In relation to therapeutic goals that SLTs set for PWA in aphasia therapy, the data show that SLTs take into consideration the achievability of goals. SLTs reported that goals in aphasia therapy are steps that lead to end results. SLTs also reported that small steps are must be realistic and achievable.

6.5.2.1 Small steps to achieve goals

SLTs viewed goals in the context of aphasia therapy as the small steps and the final state that they set and PWA aim to reach. In the extracts below, 0031s and 0021s expressed that goals are the final results that are reached by taking prior small steps.

0031s: Ok, emm, let me say it is what are the things that I can do so that I can reach my goal, the goal is the thing that I would like to reach at the end.

0021s: It is the thing that I, the thing that I am going to work on so that I can reach it, I mean at the end. It means I determine what the patient's level is and what are the results I expect from him, this is the goal; what the results that I expect, for example, before the patient is discharged.

005s and 008s expressed that the small steps or short-term goals should lead to functional goals that are aligned with PWA's needs in life.

005s: The aim of the short-term goals is that we reach a functional goal at the end, that the patient uses these activities functionally, I mean not just simple goals.

008s: I determine a certain task that enables the achievement of a certain purpose, compatible with the patient's needs and achieves the thing that I want to reach at the end, equally the same, whether communication or speech and writing improvements.

6.5.2.2 Realistic steps

SLTs viewed goals in 0016s stressed that general goals should include SMART sub-goals that lead to the final desired state. In her view, SMART goals should be realistic, specific, and tailored to PWA. This emphasis on setting SMART goals stems from the importance of identifying and reporting upon very specific goals in order to monitor PWA's progress, as well as ensuring that goals are aligned with current expectations.

0016s: The goal, as I said, is a designated thing or a designated level you want to achieve. Emm, I would not call it a goal unless there are SMART goals underneath it. Because if they were not SMART goals and they were not realistic goals, you will never reach this goal. So, we need to be smart on how to choose the goals specifically for the patient, so that he is able to reach the expected at this stage. I mean goals are long-term and short-term; short-term goals must be SMART so I can later on reach long term goals.

0016s and 0031s reported taking gradual, realistic steps and work on what is suitable for PWA based on their priorities to ensure that therapeutic goals are achievable by PWA,

0016s: Emm, we order the goals on the basis of priority and then we start to work on them according to what is suitable to the patient.

0031s: He, all the time, became asking for ‘when can I talk when? When can I chat when? When will I get back to as I was’, so, we are working on it, with him, step by step. It is true that we have goals, I mean, it is not expected that he gets back to where he was 100 percent, anyhow, now his wife tells me that he now loves to chat with them more than before he got the stroke.

Aiming also at achievability, SLTs monitor the challenge level and increase it gradually throughout the period of therapy as expressed by 008s and 0031s.

008s: At the beginning, when I started with her on reading, we started with very simple subjects, general topics, about trees, animals, plants, very simple things; we started with one-line paragraph and then we moved on little by little. Then I started with her on an academic level, I did not start with her on her discipline subjects straightaway, which is business management, I started with her on things related, like abstract thinking, subjects, for example, about intelligence and happiness, after that I moved on, with her, on her subject of knowledge, which is business management; I started with her, but in stages, we started with general topics about her field, concept about business management, what are the advantages, and so on. Then we moved on to the specific topics, like human development; also, many times I asked her to bring books from her home, the subjects that she is studying.

0031s: At the beginning when he got the stroke, we were working on only to produce any phonemic outcome, because his case was a sever apraxia. We were working only on certain sounds, but now, God willing, this has made a very good improvement for him, so we moved on to work on words and then phrases. Now we are working on functional phrases, the one he uses daily at home.

6.5.3 Sub-theme 3: Involving PWA and their family members

The data show that SLTs initiate discussions about therapeutic goals with PWA and their families to understand their perspectives on goals in aphasia therapy. SLTs viewed their input as important because of PWA's and their families' insight into their specific needs. SLTs reported that they recognise PWA's and families' personal goals.

6.5.3.1 Discussions to incorporate realistic goals

SLTs reported that discussions were initiated by them at the initial stages when the therapy plan was being developed. These discussions aim at understanding PWA's and families' goals in order to incorporate realistic goals into the therapy plan as expressed below.

0021s: As usual, the first thing in the evaluation, before we start the assessment, in the screening, the first question we ask them, 'what are your goals?', I mean the patient's goals and the family's goals, what are the goals in to of speaking, and communication, what are your goals. After that, we start the assessment process, we try to reconcile between the things, it is sometimes some of the patients have high expectation, so we try to make goals compatible, in respect to 0019, the goals were consistent with the assessment that we did.

005s: Myself, when I identified the goals and did the assessment, I took the opinion of the family in consideration, and when I put the complete plan, I took the family advice and the patient's needs and even his previous work aspects. I mean something the patient wants and likes rather than something he does not like.

005s: I was listening to them too, if they have other aspects that they want us to work on. Then, goals from the SLT and the family were compiled together, and we worked fully on them. Also, when they had questions, I tried to answer them as much as I can, praise God, their father has improved considerably.

As SLTs reported, the participation of PWA and their families in these discussions are important to understand their views and input on therapeutic goals.

008s: Of course, their participation is fundamental, at the beginning of each session I give them the goal that I am going to work on that day, and I take their opinion in that, at the end of the session again I take their opinion. If the goal was easy to achieve, what are the things that they need to add; and they know that we are open to them, they can amend, add to or remove from their goals, so in every step we need their participation.

0026s: I need to ask the patient herself, and if there were changes to the goals, of course, I will work on her goals, it will be both. I mean, my goal as an SLT and my view is considered, and it is also important to see what the patient exactly wants.

0021s: In respect to the goals of 0019p's family, it was, I mean, mostly that he become able to speak better, I mean better than now, he becomes like what he was before. They do have the ambition that he gets back to what he was before. His wife talked to me about the writing; these are the things that was in relation to him.

SLTs viewed PWA's and families' input as being important because of PWA's and families' knowledge of weaknesses and strengths, as well as the constant communication and presence of families with PWA, all of which facilitate identifying functional goals, as reported by 005s and 0026s.

005s: Of course, certainly, because they have a particular perspective. It could be the nature of the patient is different, I mean, in particular this patient, he asked for basic stuff and his basic needs. I mean some of it the family has requested it, thanks God there was improvement in his case that we reached good stages, and it was part of our goals because the onset recent.

0026s: Yes, for sure; their's is the most important thing, I mean they are the one who are living with her.

6.5.3.2 Recognising PWA's and their families' goals

Since some SLTs initiate discussions to understand PWA's and families' input, SLTs identified what PWA wanted in aphasia therapy. 005s, 0021s, 0026s expressed that PWA's goals for themselves included returning to the pre-stroke status, texting, and speaking.

005s: The patient, at the beginning, his speech was difficult, but at the beginning he was trying to express to us that he wants to speak and get back to how he was before, this is one of the points that he was trying to communicate to us with words and gestures. His case was severe at the beginning; with the help of the context we were able to understand that he would like to get back to be normal as he was before.

0026s: Let us talk about 0024p, all her goals, at the beginning of course, as any healthy person, and then suddenly got a communication disorder. So she was, how could I tell you, she wanted to speak only, that was her goal; she wants to speak!, that is fine, let us [inaudible segment]start on it step by step, so ok, for the time being let us work on the thing that enables you to, at least, speak to your family, we start with simple words and later on we work on how you talk with society on WhatsApp as you wish; So her goals, I very much considered.

SLTs also identified what family members wanted from therapy. 005s reported that the family of a participant with aphasia had goals for themselves and for their father with aphasia. They wanted to learn more about stroke and aphasia and also about supporting the communication of their father. The family aimed at functional goals for their father in therapy, as well as improving language expression and comprehension skills.

005s: In respect to their father, they wanted to be able to communicate with their father again. That is, he is able to ask for the basic things that he wants, communicate his feelings; the later on goals for the family were that he becomes able to speak and get back to what he was before, and to improve in all aspects of language, cognition and comprehension. In relation to his family, their goals were to understand more about the condition and in what way they could help their father. In relation to his family, we tried to educate the ones who are going to accompany him in the hospitals and the ones who are going to be with him at home for a while once he is discharged from the hospital.

008s, 0026 and 0031s also reported that families wanted goals for their family members with aphasia. Goals were related to increasing confidence in communicating with strangers, speaking in order to manage financial responsibilities, and increasing the length of utterances.

008s: It is certainly, the mother was always telling me that she wants her to become more daring; asks, speaks and enters into discussion at home. The mother gives us a certain scenario for anything that can happen at home, then we discuss it the three of us, me the mother and the patient, we then imagine what the things that she could enter into a discussion with.

0026s: Yes, this in relation to 0024p, ‘we [her family] want her be able to speak because she is the top financial controller at home.

0031s: The idea is that they become able to understand him, at the beginning they only wanted to understands what he wants from them, later on, little by little, when he becomes better, they expected more from him. They wanted him to say sentences, ‘you have the ability to, so yes we want longer sentences. When his wife says that he me today a four-word sentence; it is something big to them.

Although SLTs aim at incorporating PWA’s and families’ goals into therapy plan, some might have high expectations which adds a challenge on SLTs as reported in Theme five.

6.5.4 Theme three summary

Within theme three, views of SLTs were revealed in relation to how they identify therapeutic goals in aphasia therapy for PWA. SLTs take into consideration the individuality of the case of PWA, and goal achievability. SLTs also involve PWA and their families by initiating discussions to understand their perspectives in order to incorporate realistic goals.

SLTs expressed that strengths and weaknesses of PWA are considered by conducting informal assessments, in addition to the functional needs of PWA. SLTs also reported that identifying small steps to reach realistic goals, and monitoring goals' level for better achievability are considered when setting goals in aphasia therapy. SLTs expressed involving PWA and their families by discussing therapeutic goals. SLTs expressed that they consider what PWA and their families want in therapy and aim to incorporate their goals in therapy. They reported initiating discussions at initial stages of therapy and also through the rehabilitation period in order to understand PWA's and families' perspective in relation to therapeutic goals. SLTs viewed PWA's and families' input in these discussions as important because PWA and their families have an insight into their own needs which facilitates setting functional goals in aphasia therapy. SLTs recognised PWA's and families' goals in aphasia therapy; however, incorporating some of their goals can be challenging because of the presence of high expectations as reported later in theme five.

6.6 Theme four: Participation in goal-setting

Theme four reveals participants views on the participation of PWA and their family members in setting therapeutic goals alongside SLTs in the Saudi context of aphasia therapy. Moreover, the theme incorporates the factors that could influence such participation. The details of theme three are as follows:

- Sub-theme 1: The extent of participation in goal-setting.
  - Sharing personal goals.
  - Trusting SLTs as decision makers.
- Sub-theme 2: Factors influencing effective participation in discussions about goals.
  - Condition-related factors.

- Knowledge of stroke and aphasia.
- Family presence in therapy sessions.
- Service-related factors.

A detailed structure of theme four, which illustrates results and contributing views, is presented below in Figure 6.10.

6.6.1 Sub-theme 1: The extent of participation in goal-setting

Sub-theme 1 presents the extent of PWA's and families' participation in goal-setting from the viewpoints of all participant groups (PWA, family members, and SLTs). This sub-theme presents their views on sharing their input on goals, in addition to justifications for the non-participation.

6.6.1.1 Sharing personal goals

Few participants with aphasia reported participating in choosing therapeutic goals alongside their SLTs. Their participation was in the form of sharing their personal goals including value-based goals which reflects the strong presence of Islamic faith in PWA's culture. 0029p informed his SLT of his desire to practise reading the Quran, as she feels that the religious aspect is an essential area in their lives.

HA: Who chose the goals for your speech therapy sessions?
0029p: They did.
HA: The specialists?
0029p: Yes.
HA: Did you help the SLT in the goal selection?
0029p: I do not remember.
HA: You reported that you told her you wanted Quran
0029p: Yes, last time.

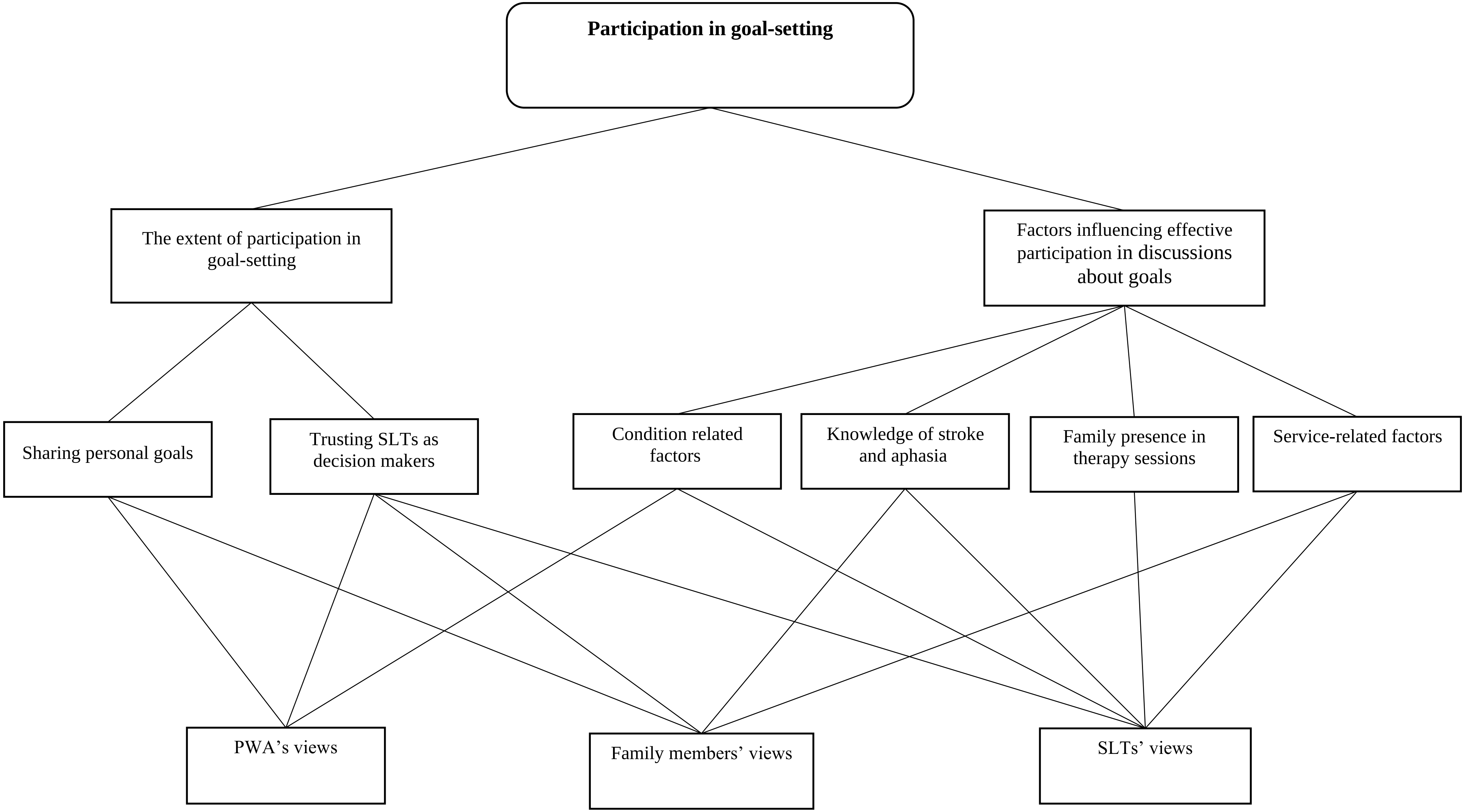


Figure 6.10 Theme four details and contributing views

0024p also shared her desire to practice on reading the Quran which reflects also that PWA value religious activity goals in the Saudi context of aphasia therapy, and that religious activities are affected by stroke and aphasia.

HA: Did you help the specialist in choosing therapy goals?
0024p: Yes, I did.
HA: Like what?
0024p: I told her I could not read the Quran or to think about it my mind, like an illiterate person who cannot read. This is what has happened in my brain; I cannot read or even speak.
HA: You suggested the Quran to her so that you practice reading and become better.
0024p: Yes.

0024p reported that participation in choosing goals alongside SLTs is important. She attributed such high importance of participation to the fact that the person with aphasia knows his/her own weaknesses and strengths better than anyone else. Thus, they can share and set functional goals that are aligned with their abilities and needs in life

HA: Do you think it is important to help the SLT in choosing aphasia therapy goals?
0024p: Yes, I do.
HA: Why is that?
0024p: Because he is the one, I mean he is the one who is aware of himself.
HA: The patient is the one who know what he needs?
0024p : Yes.
[Participant chose 5 in a 5-point scale. 5 is very important while 1 is not important at all]

In relation to the family members, 0018f and 004f reported that their participation was in the form of discussions and sharing input during the period of therapy.

0018f: No, sometimes in the sessions, I talk to the speech therapist that we said such and such [inaudible segment] replacing, especially replacing, and the sentence structure, and later on, anyhow, little by little it became ok.

004f reported sharing religious activity goals with the SLT to help his father practice reading the Quran and perform prayers reflecting also the value of such goals in the Saudi context.

004f: Honestly, I have suggested, at the beginning of the week, that there should be more focus on the religious aspect, because he has forgotten the religious matters totally, be it the Quran verses or how to perform the prayer; so I told them to focus on the religious aspects a little bit.

0018f and 004f viewed their participation as being highly important. They associated such importance to the fact that they are the individuals accompanying, observing and spending most time with PWA. Therefore, they can identify goals that are functional and desired by PWA as in the extracts below.

HA: Ok, could you tell me, what is the importance of the family members' participation in choosing goals, why this is important for them?
0018f: The closest ones to the patient are the family members.
HA: Yes.
0018f: Because they are the one, I mean, live their daily lives with them, I mean.

004f: I expect it is something important sometimes, because the individual, who sit for an hour or half an hour, would not notice the same things that someone else, who sit with the patient for six to eight hours.

6.6.1.2 Trusting SLTs as decision makers

Most PWA reported that they did not participate in identifying therapeutic goals alongside SLTs. The extracts below are some examples.

HA: Did you help the SLT in choosing therapy goals?
009p: No, I did not, I said whatever you see.
HA: You told them, whatever you see?
009p: Yes.

Another participant with aphasia reported her desire to work on mobile phone texting during the interview with the researcher. However, the participant expressed some hesitation with respect to sharing that goal with her SLT.

HA: I mean, do you remember a goal that you wanted, and asked ___ to work on this goal?
0017p: No, [inaudible segment], the mobile texting, I did not speak about it.
HA: But you would like to?
0017p: Yes
HA: Are you going to talk to him about this matter?
0017p: [body language indicating that she is not willing to share with SLT]
HA: No! you reported you wanted your writing to become better in general, whether like this or on the mobile; at this period of time you are going to work on it, he told said he is going to work on writing with you.
0017p: Yes.
HA: Are you going to inform him that you want mobile texting?
0017p: I do not know.

PWA attributed their non-participation in goal-setting to the trust that they have in SLTs as healthcare professionals who possess knowledge on the medical condition and the means by which to reach the desired outcome. Hence, reflecting their views on SLTs as main decision makers in the process of goal-setting.

HA: You did not choose with them?
0022p: No, because they are, I mean, speech related and like.

HA: Did you help her, that you told her that there are goals you would like to work on?
006p: No, I did not.
HA: You mean you did not help her in choosing therapy goals. Ok, why you did not tell her, for example, that there something I want to work on?
006p: She is the doctor, and she understands what I want.

0019p reported that participating with SLTs in choosing therapeutic goals in aphasia therapy is relatively important in order to share functional and desired goals. However, he reported that he did not participate because of his trust in the expertise of SLTs. This reflects PWA's appreciation of being involved and listened to, but preferring decisions to be made by the professional experts.

HA: Did you help the SLT in choosing therapy goals?
0019p: No.
HA: Ok, why?
0019p: They are the [inaudible segment]. You have, God will, but only you have in [inaudible segment] reading the word, the written words.
HA: You mean they are the one who said you have weakness here and there?
0019p: Yes, exactly, we need to fix this and that.

HA: Do you think it is important to help the SLT in choosing aphasia therapy goals?
0019p: Yes.
HA: Ok, why is this important?
0019p: There are things he wants [inaudible segment] he wants, wants like for example, there are things like I want [inaudible segment].
Before, I couldn’t [inaudible segment] ok, and I went to the doctor and told her how [inaudible segment] how I don’t know now [inaudible segment].
Before, nothing I know, nothing I mean. For example, I want “Ma’soob” I couldn’t before, I did not know it. Every day “Ma’soob” “Ma’soob” until it came back.
HA: You mean there are certain words you use a lot in your daily life that you want to practice on?
0019p: exactly.
HA: Ok, you said it is important for you to choose goals with the SLT, how important is this?
0019p: Half and half.

[participant chose 3 in a 5-point scale. 5 is very important while 1 is not important at all]

The majority of family members reported non-participation in goal-setting as well. The extracts below provide some examples.

HA: How goals of speech and language therapy were chosen?
0020f: The doctor, I did not interfere.

HA: How goals of speech and language therapy were chosen?
0028f: The specialist chose them.
HA: Did you participate in the process of choosing goals?
0028f: No, I did not participate.

Similar to PWA, the main reason for the non-participation of family members in goal-setting is that of trust in SLTs' knowledge and experience with regard to setting the most appropriate goals for that lead to progress in the case.

HA: Ok, why did not you participate? Was there a reason or not?
0028f: There was not a reason, nothing, what I mean, I do not have a full background of what I [inaudible segment]; it is to do with the specialist.

0030f who did not view participation as being important attributed that to SLTs' knowledge and families' trust in them as experts in the profession of speech and language therapy.

HA: Did you participate with the SLT in choosing therapy goals? Did you suggest anything for example?
0030f: No. she knows, to be honest we don't know what are the means to achieve. I do whatever they ask me to, I don't know.
HA: The steps you take to achieve.
0030f: Yes, for example, like cardiologists, we don't know what to do, we do what they instruct, but we don't know.

0030f: We think that the specialist is knowledgeable in this area, we don't know. Maybe we suggest something that is not for the patient's best. For example, I might say something for a patient with heart disease that is not for his best, If I say to stop his medications, the doctor would say no because he is knowledgeable.

004f expressed that trust in health care professionals is present among people receiving rehabilitation services because they possess the knowledge that can help to improve.

004f: Sometimes I notice a thing, my father’s response to the health specialist is better than his response with us. I mean, for example, with a speech therapist, he responds to everything he asks for.
HA: Ok, why?
004f: Generally speaking, I expect that patients trust more in therapists being the ones who can provide help.
HA: Is it trust or an obligation?
004f: No, I expect it is trust in the useful person.

Similar to the case of 0019p above, 0014f reported that the participation is important; however, she did not share goals with the SLT. This reflects the family member’s appreciation of being listened to, but preferring SLTs to take the role of main decision makers.

HA: Do you believe that it is important, for you as a member of the family, to help in choosing therapy goals?
0014f: Yes.
HA: Did you choose goals alongside the SLT?
0014f: I chose whatever she sets.

The reported non-participation of families and PWA in setting therapeutic goals is evident in SLTs’ data. 0031s, reported that therapeutic goals were set by them and agreed upon by PWA and their families.

0031s: No, we only told them that this is our goal, and, what I mean, they agreed on it and they said, ok, no problem, the important thing is that he speaks.

In one of 0016s' cases, the SLT viewed the non-participation of the person with aphasia and his wife as a sign of trust in and respect for the SLT's role as a healthcare professional which also reflects SLTs role as main decision makers in the process of goal-setting.

0016s: He feels confident to our goals as a speech therapist and he appreciates our assessment.

0016s: Emmm, she was Emmm, on the opposite, I mean his wife did not interfere, she was feeling that this is my job, so she did not try to interfere except in the cases where it was right to do. I mean for example, if he did not get cueing form me, or different dialect. For example, if I give him a name of something in a different accent, she corrects me or tell him in their accent, that she means that, so he understands her, so she was helping me in this way, but I always go back and ask her, was his answer right? For example, when I ask him, how many children do you have? How many daughters do you have? These questions when he answers them, she was helping me with the answers without making the patient aware that she was assisting me.

6.6.2 Sub-theme 2: Factors influencing effective participation in discussions about goals

In this sub-theme, participants share views on influential factors they think it could either facilitate or hinder an effective participation of PWA and their families in goal-setting in aphasia therapy. Four factor groups were identified within this sub-theme. These include condition-related factors, knowledge of stroke and aphasia, family presence in therapy sessions, and service-related factors.

6.6.2.1 Condition-related factors

009p reported that the participation of PWA in goal-setting is important, but sometimes it is challenging to participate due to the expressive difficulties of PWA.

HA: Do you think it is important to help the SLT in choosing aphasia therapy goals?
009p: He cannot.
HA: Why?

009p: The person [with aphasia] cannot understand what is said.

SLTs reported that the severity is a factor affecting participation. The severity of aphasia could hinder PWA in providing their own input as reported by 008s.

008s: Of course, at the beginning she did not want to tell me her goals, she was trying to talk, so I considered the goals I identified. When she became verbal and can talk, yes, every few weeks, I and her, we revisit the goals, and she tells me what she want, the reading, for example, is easy for her and she wants something harder this time, or when we reach a hard level she asks me to go a level down. Yes, I am sharing every step with her.

In addition to the severity of cases, the onset and type of stroke, the psychological status, cognitive abilities, co-morbid conditions, prognosis, age are also influential factors as expressed by SLTs in the extracts below.

HA: For the patients in general, what are, in your opinion, the other possible factors?
005s: The factors are many; psychological factors, cognitive factors and the impact of stroke location and severity.

008s: Prognosis is very important, and their awareness of what is being said to them is very important. The emotional psychological status of the patient is very important, it could be a help and it could be a hinderance.

008s: The age of the patient as well; if the patient is an old age patient, the family is satisfied if they patient can walk regardless of speech. Onset of stroke, of course if it was acute or chronic stroke.

008s reported that sometimes in clinical practice, and when aphasia is severe but other physical aspects had improved, other team members might shorten the inpatient rehabilitation period.

008s: Unfortunately, as I said to you, here, the doctors, if they see the patient moves and walks, they shorten the length of the admission period. The severity of cases; sometimes, it is unfair for server global aphasia cases, the OTs and the PTs are put in a situation where they do not know what how to deal with them, so they shorten the admission period, or they don't set functional goals for them, so they say let the speech therapist see them as outpatients.

6.6.2.2 Knowledge of stroke and aphasia

0031s reported that knowledge was a factor influencing participation most of the time as she observed in her clinical practice.

0031s: I mean there are people who do not understand at all what is speech therapy, there are many people that are passive, ok fine, but what are your goals? 'Only want him speaks', this is 90% of the patients that we see, only a small percentage of them tell you that they want to be able to understand him and he understands them.

0026 viewed not participating in goal-setting to the insufficient knowledge of stroke and aphasia and the lack of awareness in society. Moreover, 0016s viewed the lack of awareness as reflected in the difficulty that family members encounter during the first stages of therapy when being educated about stroke and aphasia. Family members and PWA arrive with no previous information on these issues, which might pose a challenge for them in understanding all provided information at once.

0026s: Emm, it is about goal-setting and participation is the most thing [inaudible segment], so, we have discussed it before, I mean because it is a new thing, there is no one in the same family, the family members or the patient him/herself able to set goals. This is because, it is not known that aphasia is an important thing. It is something no one knows until it happens to them, apart from that, no one hears about aphasia.

0016s: Emm, the cases, many people are not aware, I mean they do not know what aphasia is, in general neither the family members nor the patients are aware. I mean even when I explain for them, at the beginning they do not comprehend it, they respond with "no but he understand but why he is not able to speak", so there is not enough awareness in our society in respect to diagnosis, this means exactly, that there is not many people know a lot about aphasia.

The knowledge on stroke and aphasia with which PWA and their families attend therapy is important to participation in goal-setting as SLTs reported in the extracts below.

0016s: Their understanding of the case, I feel it makes a difference, I mean they must understand what is aphasia, what is the current level, and why this is happening, I feel this has effects.

008s: The education makes it a lot easier, be it the patient or the parents themselves; equally the same, whether on the educational level or the awareness level of what is happening.

0021s: Mostly, I mean, if the patient and the family have comprehensive awareness of the condition, comprehensive understanding of the patient's case, I feel it is not at all difficult for them to identify goals. Usually it is easy for them to identify goals unless the family sometimes, I mean it is possible we see patients who are not educated and sometimes do not comprehend the problem itself, or they do not believe in the speech treatment to start with, so here, in this situation, we face a problem in goal-setting, I mean, it could be that we identify goals and they feel like 'ok, what is the benefit that he speaks more', especially, the patients with mild or moderate cases, here we face some of the problems, I mean, if they were not educated.

From the viewpoints of some SLTs, the late initiation of participation is observed in PWA and their families. SLTs attributed such late participation to the insufficient knowledge in the early stages of therapy as reported by 0026s.

0026s: In their respect, and in general any individual that have aphasia, it is a new thing for them, the first time they experience it, I mean most of them it is their first time. At the same time, they are unable to set goals because they do not know what has happened, I mean what is the nature of the aphasia to start with, why he does not speak, is it because she does not want to; some of them they felt that there is a psychological problem, or a problem and she will never be able to speak again, because basically she had cognitive impairment, so she will not be able to make decisions and will not be able to speak. It is because of that, at the beginning [inaudible segment] I identified goals that would help the patient, later on when we were able to cooperate with the family, I involved them in the goals, the goal-setting, and I worked on their goals as I said before; Quran, how to pray, how to talk, how [inaudible segment] how to manage my home.

0026s expressed that 0024p's participation was at a later stage. She attributed the inability of PWA to participate in early stages of therapy to the insufficient knowledge of stroke and aphasia.

0026s: The Quran, because she said she wanted to work on such and such and such, but this is later on. At the beginning no, I told you, it is because, however you explain to them about aphasia, it is still a new thing for them, so the family are like ok, you are the speech therapist and you are the one to do it.
HA: you mean at a later stage of therapy they start to give their input.
0026s: Yes, exactly.

0012f reported explicitly that his participation in choosing goals for his son was in a later stage of therapy. Such late participation is justified by the increased awareness that the family gained after a period of time.

0012f: Yes, I started, I started to give them the opinions, that we are still in need to focus on that, and focus on the language more than that, focus on the right leg because it started to incline,; of course that has happened, but it was late.
HA: You mean when they identified the goals, they identified them themselves, and later on you started to participate with giving your opinion, like let's focus on that.
0012f: No, no, not even that, we did not start, we did not start [inaudible segment], only just now, now.
HA: You mean after, how long?
0012f: The second admission, the second admission is when I started to talk because I am now aware, and you know [inaudible segment].

0023f reported the need for awareness to understand the case and be able to participate effectively.

0023f: Yes, there are factors; sometimes the family needs and intense awareness.

6.6.2.3 Family presence in therapy sessions

0026s and 0031s believes that the presence of family members in therapy sessions is a factor related to effective participation in goal-setting. When family members do not attend the sessions or attend with PWA intermittently, the communication between them and SLTs becomes more difficult, thus hindering their participation in setting goals.

0026s: Changing the watcher [the patient companion] many times, the reasons are like, they sent a watcher that is not qualified to identify goals, this is for example in relation to the patient, this is one of the most important things, for example it is a little girl, she does not know exactly, so she will not give you a reliable answer to start with, and will not give you a realistic goal for the patient.

0026s: Yes, there was a long discussion about this, sometimes the family themselves, sometimes they are not there, all of them; sometimes for a reason such as the girls are in the university and her husband is not available, so she comes with a caregiver. It is hard to communicate with them, because when could we communicate with them? so the discussion happens only at the family meetings for example or at discharge time, but most of the time we do not see them, this is one of the reasons, the family of the patient has no time during the working hours to be seen in relation to the patient, this is one of the problems.

0031s: Discontinuity in sessions does not enable them to continue it with you, it does not let them determine what the goals are, they do not want.

6.6.2.4 Service-related factors

From the viewpoints of family members, different elements related to services are considered influential factors in their participation. These include SLTs' good manners, the need for supporting the involvement of PWA and their families, and the insufficient aphasia services that can hinder an effective communication and seeking further therapy.

0010f expressed that SLTs good manner is an essential aspect that either facilitates or hinders effective communication with respect to sharing goals.

0010f: The good manners.
HA: The manners.
0010f: Some of the specialists speak with a down look on, some of them speak to an elderly as it was their father or their brother or sister, this one I speak to her with no problem, but the snobbish one, whenever he is assigned with her, I go and look for another one for him.

In relation to supporting the involvement of PWA and their families, 0018f expressed that it is essential to be informed of therapeutic goals and goal achievements periodically. In his experience, the SLT did not share such information with him as a family member to a person with aphasia.

0018f: I mean, it is for sure the quality, I mean the evaluation before and after. I mean, in relation to hospitals and goals. I went to Czechia and they informed us about the goal, activity and skill that will be achieved in this period of time for example; but I did not see this here.

HA: The specialists here did not clarify for you, for example, working on this goal in this period of time?
0018f: No.

One family member attributed his non-participation to the fact that the SLT did not ask for his goal-setting participation explicitly.

HA: Did you participate in choosing therapy goals?
0020f: No, they did not ask us at all to; the hospital.

Visual materials with which to follow up on progress or record notes on goals and performance are another factor reported by family members.

004f: If the companion has a note book, to note down the things that the patient repeatedly tries to convey but cannot speak of, and the companion inform them to the specialist, this will be a positive input in the treatment session.

Factors related to insufficient aphasia services are another area reported by SLTs and family members. From the viewpoints of SLTs, the insufficient aphasia services and the fact that some PWA and their families travel from different cities in order to receive rehabilitative services are influential factors in the effective participation of PWA and family members in goal-setting.

0026s: The second problem is if they were coming from outside of Riyadh, this is one of the things.

008s reported that therapy continuation in the form of outpatient services was facilitated for 006s because she lived in Riyadh, wherein such services are provided.

008s: When they were discharges, I provided them with a program and then I started outpatient sessions with her as they were living in Riyadh.

Not only are rehabilitative services being mainly available in large cities, they are also limited in terms of the number of beds, as expressed by a family member. As 004f explained, rehabilitative services need to be expanded.

004f: I met a specialist in the department of rehabilitation in the university hospital and discussed this rehabilitation matter.
HA: In ___ University?
004f: Yes, in ___ University, he said that the total rehabilitation beds do not exceed 200 beds in Saudi.

When rehabilitative services are insufficient and available in the capital city or to big cities, a pressure appears to be imposed upon SLTs as healthcare service providers in relation to session slots. 0018f expressed that limited session slots are a main factor influencing sharing input with the SLT.

0018f: The limitations of the appointments, you are tied down to a certain appointment, and he has hardly a twenty minutes to speak to you, and if you speak or suggest and so, it is like you took some of the patient’s time while it is a golden opportunity to exercise.

Since sessions are dedicated mostly to PWA, and because slots could be far apart, 004f suggested conducting weekly meetings with the SLT in order to discuss the case and share progress.

004f: If there was at least one session, at the beginning of the week, between the specialist and the companion to discuss what the things that are needed or what are the things that are lacking in relation to the patient, or the things that he asks for continuously.

The Venn diagram below (Figure 6.11) illustrates views on factors that could play the role of barriers or facilitators with regard to participation in goal-setting.

6.6.3 Theme four summary

Within theme four, views were revealed on the participation of PWA and their families in goal-setting alongside SLTs. Different issues were raised including the extent of PWA’s and their families’ participation, and the factors influencing the participation of PWA and their families in discussions surrounding therapeutic goals in aphasia therapy.

Some PWA and their families reported sharing their input with SLTs, and expressed that the participation in setting therapeutic goals alongside SLTs is important. PWA and their families attributed such importance to their insight into their specific needs.

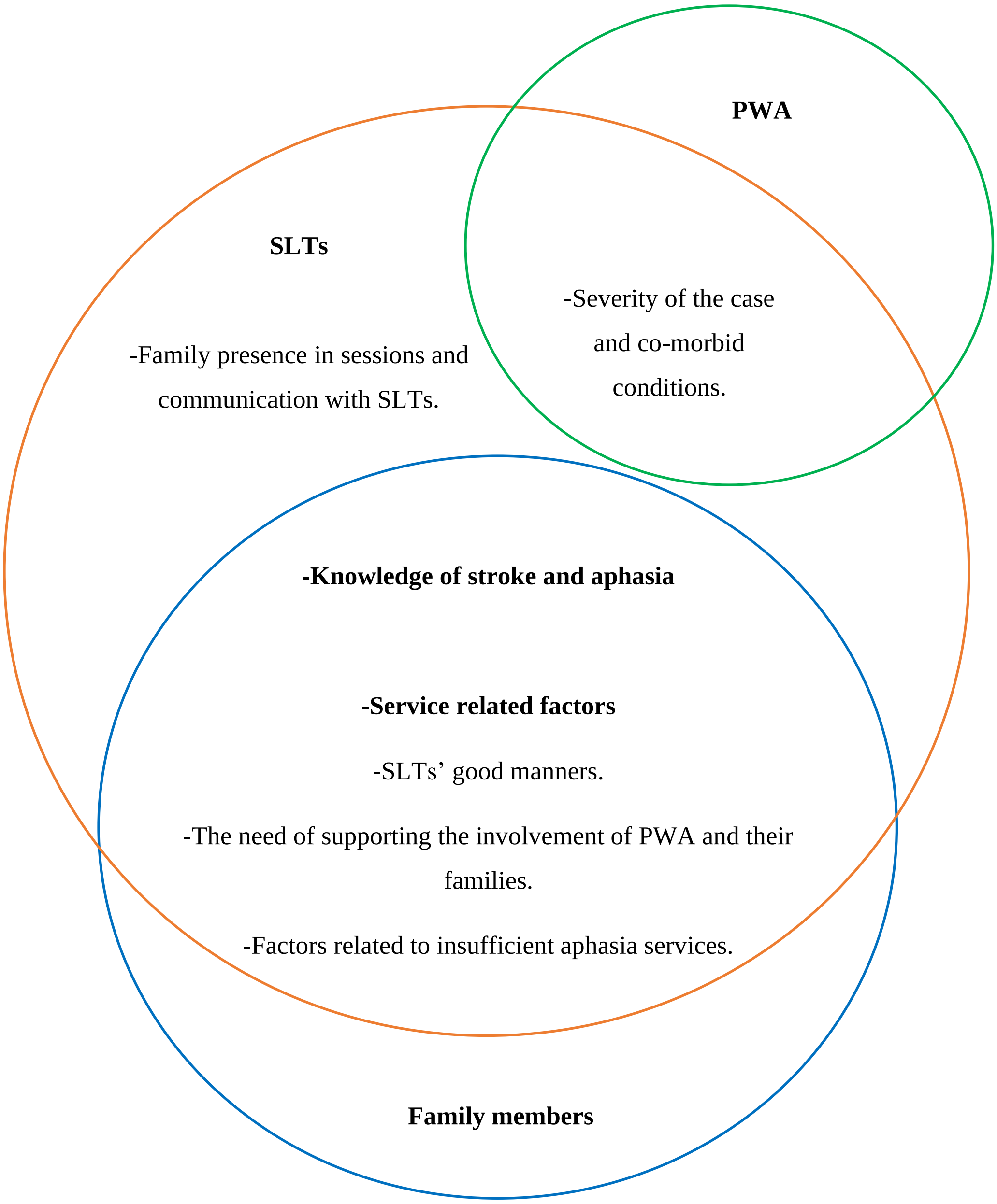


Figure 6.11 Factors influencing effective participation in discussions about goals

PWA and their families reported sharing goals that reflected their religious values the importance of such activities in PWA's culture. They reported that they wanted to practice on reading the Quran and performing religious prayer.

Some reported that they did not participate in goal-setting alongside SLTs suggesting that SLTs are viewed as main decision makers in aphasia therapy. The non-participation was related mainly to the trust in SLTs as professionals who possess the needed knowledge to improve. Some participants reported that participation is important, yet they reported a non-participation which reflects their appreciation of being involved and listened to, but trusting SLTs as main decision makers in relation to therapeutic goals.

Participants reported factors that can influence effective participation in discussions about therapeutic goals. These factors include condition-related factors (severity of aphasia and co-morbid conditions), knowledge of stroke and aphasia, and family presence in therapy sessions. Moreover, participant reported service-related factors including SLTs' good manners, the need of supporting the involvement of PWA and their families, and insufficient aphasia services.

6.7 Theme five: Expectations in aphasia therapy

Theme five presents expectations in aphasia therapy as appeared in participant's data. The theme presents matched and unmatched expectations from participants' views. Then, theme five presents how SLTs manage expectation in aphasia therapy. The details of theme five are as follows:

- Sub-theme 1: Matched and unmatched expectations.

- Matched expectations and effective participation.
- Unmatched expectations and negative impact on aphasia therapy.

- Sub-theme 2: Managing expectations.

- Reconciling goals.
- PWA and family education.

A detailed structure of theme five, which illustrates results and contributing views, is presented below in Figure 6.12.

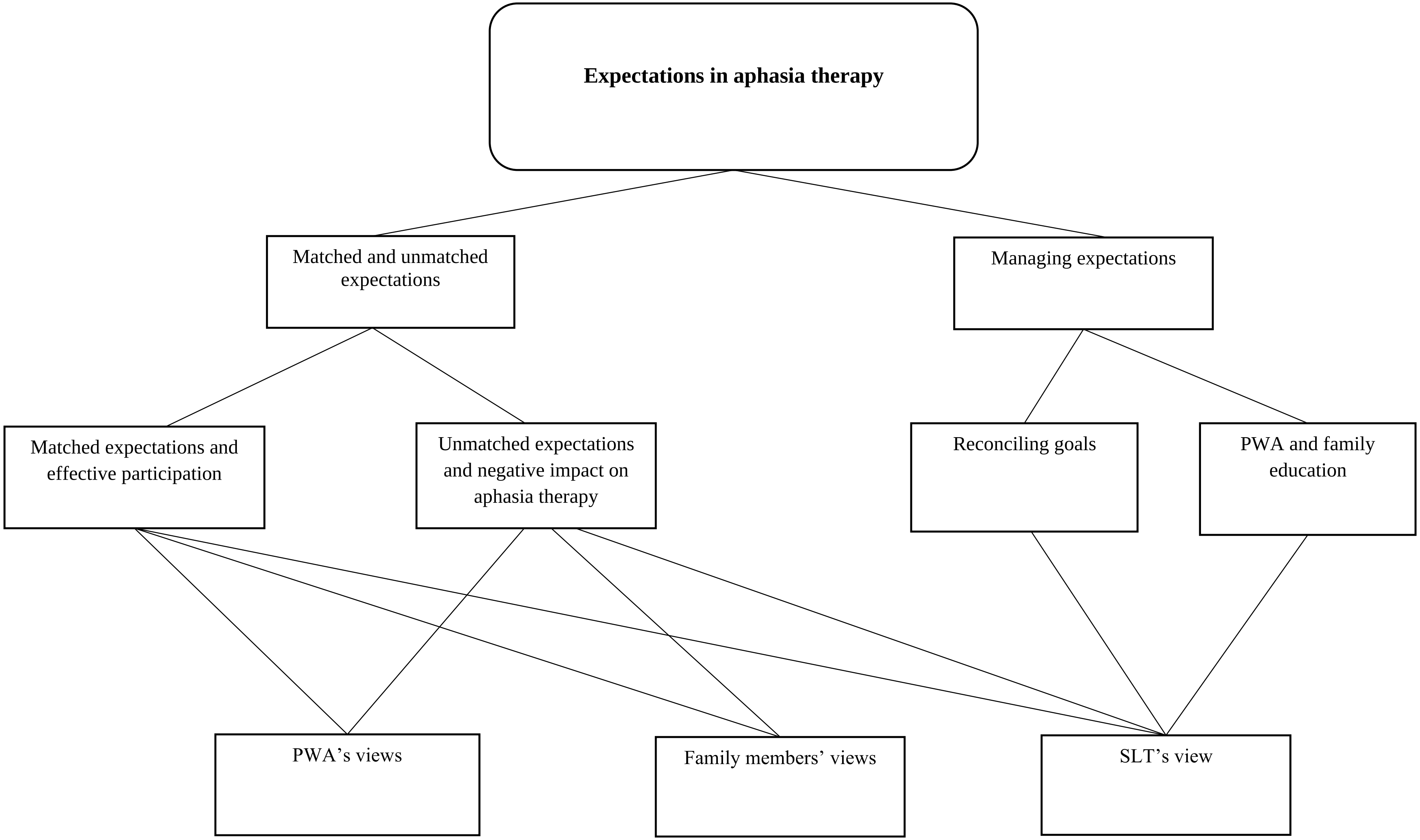


Figure 6.12 Theme five details and contributing views

6.7.1 Sub theme 1: Matched and unmatched expectations

Sub-theme 1 presents matched expectations in relation therapeutic goals in aphasia therapy, and also the views of SLTs on increased participation as a facilitator of reaching matched expectations. This sub-theme also presents unmatched expectations of participants and its negative influence on aphasia therapy.

6.7.1.1 Matched expectations and effective participation

Some PWA expressed that additions to their speech therapy sessions are not needed, thus reflecting matched expectations in relation to therapeutic goals as in the following extracts.

HA: Nice, ok, this is what you do in the sessions. Is there a thing that you would like to do, but you did not have the chance to do with the SLT? I mean, is there a thing on your mind that you want to do?
006p: No.

HA: Is there any other thing you would like to do in speech therapy sessions?
0024p: No.
HA: You mean all what you want, you are working on.

HA: Is there any other thing you would like to do in the speech therapy sessions?
0027p: No.
HA: You do everything you want?
0027: Yes.
HA: Great.

One family member reported that expectations are matched in therapy in terms of goals, as he expressed explicitly that all goals are covered in therapy for his father with aphasia, thus reflecting that the goals of families are matching those of SLTs.

004f: I expect that he is covering all the goals, however sometimes, I noticed something, it is that, my father is better receptive to the health specialists than to us; I mean for example, with the speech therapist, he engages with him in everything he asks from him, with me for example, I ask something from him, he tells me 'leave me alone, let me have a rest', that is it.

Matched expectations between SLTs and PWA on therapeutic goals emerged from SLTs' data as in the extract below. 0021s reported that she and her patient with aphasia have matched expectations in relation to therapeutic goals.

0021s: In relation to patient 0019p, the goals were, I mean in sync with the assessment that we did.
HA: Do you think, approximately, that your goals and the patient's goals were matching?
0021s: Yes, they were.

0016s: When I ask him 'would you like another thing?' when I ask him about the words, he feels like 'ok, I'm with you I agree with the goals you put'.

0016s expressed that when her goals were compatible with the family member's goals, cooperation was observed in therapy.

0016s: Emm, I mean his wife was accompanying him; she was very cooperative and listens very well to us, emm she did not have a certain path, the important thing to her was that he communicates in general. I mean he is the one who puts the greater pressure on himself than what his wife puts on him, I mean yes, she was very cooperative with us and she was understanding, I mean she gives verbal understanding. Her goals were compatible with mine. At the beginning, as I said to you, she used to say the most important thing is that he speaks; at least to say, ask, do. After she understood the case, she was cooperative and was following our goals.

SLTs reported that the participation of PWA and families is appreciated because of issues related to expectations in therapy. When all triad members (PWA, family members, and SLTs) participate effectively in discussions surrounding therapeutic goals, expectations appear to be similar, which enhances cooperation in achieving goals as reported by SLTs in the extracts below.

0031s: Of course, if there was no participation, from them, in the goals, they would not be cooperative with me. The requests that I would ask them to do at home would not be done, because they would not be convinced. It is very important that they are convinced and satisfied in what they are doing, and also know why they are doing these things

008s: Of course, it is important, because most of the work depends on them, because the patient mostly will communicate with them; also, because they know what are the goals that would make the patient more functional. Also, they must be convinced with the goals, so that they will work on them, because if they were not convinced, they would not work on them.

0016s: Emm, I mean his wife was accompanying him; she was very cooperative and listens very well to us, emm she did not have a certain path, the important thing to her was that he communicates in general. I mean he is the one who puts the greater pressure on himself than what his wife puts on him, I mean yes, she was very cooperative with us and she was understanding, I mean she gives verbal understanding. Her goals were compatible with mine. At the beginning, as I said to you, she used to say the most important thing is that he speaks; at least to say, ask, do. After she understood the case, she was cooperative and was following our goals.

Motivation, cooperation and commitment to therapy could add a positive impact on PWA to improve as SLTs expressed in the extracts below.

008s: Yes, they have stayed a long time in admission, a period ranging from 6 to 8 weeks. Her mother was with her and she herself was greatly motivated in the beginning. That was driving us forward and especially as the stroke onset was recent; two or three months maximum.

005s: To be honest, the patient himself was motivated and willing. He comes to the sessions at time, and I feel that he comes with the motivation to improve. There are patients other than him with no motivation, and the family are not cooperative, but with this patient, he is motivated and his family are cooperative and listen to instructions within and outside the session aiming to improve the language, comprehension and cognition.

6.7.1.2 Unmatched expectations and negative impact on aphasia therapy

Although matched expectations were reported by some participants, unmatched expectations were also present in aphasia therapy. Having high expectations or different expectations on therapeutic goals and activities was evident in participant groups' data. PWA expressed that they wanted to work on goals that were not set in their therapy plan. 0017p felt ready to work on writing, while 0022p wanted some cognitive exercises.

HA: Is there any other thing you would like to do in the speech therapy sessions?
0017p: I want [inaudible segment] writing.
HA: You want writing.
0017p: I swear I do.
HA: You feel the time for writing has come, you want to start practicing.
0017p: Yes

0022p: We change it, like I mean, I mean it is a photo and they will later on rearrange it, and then, I am like, I mean I am trying to.
HA: You want changes in activities? you want like photo puzzle?
0022p: Yes, to change, instead of speaking and speaking, because it is important for the brain and so.

Having high expectations in relation to therapeutic goals is evident in respect of participant 003p. In the participant's view, therapeutic goals and activities were helping him to improve but not as he expected.

HA: Activities as you do with ___; do you feel they are enough, or you need more other things?
003p: That helps me a little bit only.

From the viewpoint of another participant with aphasia, the challenge level of therapeutic goals and activities is above that of his abilities. This, in turn, left 009p feeling that he is not progressing, and then losing motivation as in the extracts below.

HA: Do you work on the questions? I mean, she asks a question and tells you to answer back?
009p: Yes, but I could not do it,
HA: But surely by time you will be able to.
009p: Time after time, it became many, many times.

HA: Is there any other thing you would like to do in the speech therapy sessions?
009p: No, nothing.
HA: They do everything with you?
009p: They do everything with me, the do everything but I do not want it.
HA: You do not want it!
[Pause]
009p: I do not want them to do things I do not want.

As with PWA, family members had different expectations on therapeutic goals as well. 0018f, who is the husband of a participant with aphasia, was wondering why expressing emotions is not targeted as a goal in the therapy plan, since his wife faces difficulty with that.

0018f: For example, why don’t we have a plan to restore feelings and emotions? I mean sometimes, do you know how the doll repeats expressions over and over to the extent that you don’t notice it anymore? This is how she is, repeating same expressions and words, I mean there is a lack in her vocabulary.

The daughter of a participant with aphasia and the father of another participant with aphasia had high expectations, both of whom wanted to increase the challenge level in relation to goals in aphasia therapy. 0023p thinks that increasing the ceiling of expectations in therapy is needed in order to push her mother to perform at her maximum potential and then to progress. Moreover, she thinks that therapy needs to be intense in terms of session intervals.

0023f: When you provoke her, you give her a chance to talk. If you give her the information at ease, that would give her no incentive to talk. It is even when she plays an audio of the Quran, she reads with it a little bit and then she goes silent, she needs some kind of pushing force.

0023f: Yes, when I raise my expectation level, the effort will be more, it is true that it will take more time, but the results will be good.

0023f: Therapy must be dense. Sometimes when the session appointments are far apart, she relaxes, and sometimes when we give her the information with ease, it is like you made it easier for her.

0012p also had high expectations on therapy outcomes related to his son. In his view, his son should be able to produce at least three to four sentences, while his son had moderate expressive aphasia.

0012f: Sentences, we want him to produce sentences, we want him to speak, for example, two or three sentences at least. Three sentences, such that he speaks them fully in one go, not one sentence, like ‘close the door’ and that is it. I want at least three or four sentences, at least three to four sentences I mean.

SLTs’ data show the presence of unmatched expectations, and shows that mismatched expectations could be present at the level of therapeutic activities or goals between PWA, families, and SLTs. SLTs and PWA could have similar general goals, but expectations on the methods through which to reach the desired goals might differ as reported by 0016s.

0016s: The patient desires to speak, emm, and I do have the same goals, but using means that he doesn't expect, imagine, or realise that these means will help him to improve verbal expression. I mean he feels ‘I want to talk, but train me on how to talk’, or repetition. He thinks that only verbal repetition is a goal. I mean we are nearly matching the same goals, but I already explained for the patients the techniques, and how we will improve verbal expression using these techniques. I mean it is close to our goals for him.

The higher unmatched expectations that PWA and families sometimes have could impose a negative impact upon therapy. Having high expectations could influence the motivation of PWA and their families negatively as 008s reported.

008s: High expectation, be it from the family or the patient, that she return to normal state, this can be a hinderance for us and for them, for them it could be that they leave us and see later on we did not achieve all the goals and her state did not come back to normal, it give them a motive not to come to the regular therapy outpatient session.

In addition to motivation, having different expectations could influence the level of cooperation in aphasia therapy.

0015s: Factors that helps when we do; the most important thing is the education, once I have done the education and felt that the family understood the goals it becomes easier, they understand and become cooperative with me in the sessions, but when they do not understand the case, they do not understand why we chose these goals, the will not, I mean they come back and ask ‘why do not you do this, why do not we do that, why he is like that to start with’. Someone comes and ask me to set an advanced goal, for example doesn't fit his case.

In other situations, high expectations could impose negative impact on PWA. As in the following extracts, families could have higher expectations and unrealistic goals with respect to a non-fluent patient with aphasia reaching a conversation level in the early stages of therapy.

0016s: They want him to speak and chat; to speak at a conversation level, which is impossible. Not impossible; impossible for the right time, for the current time.

HA: Yes.
0016s: It’s impossible, I mean it is, I can’t put a goal ‘patient will reach conversation level’ this non-realistic goal. That is why I told you he needs education.

0016s: The father only, the father is the one who gives me goals that are higher than the level that we determined, and I was telling him that every time, but he feels that if he keeps doing it he will get some results. At the beginning, he was giving me goals that are mostly additional, it means non-realistic.

When families have higher unmatched expectations, they could push PWA beyond their abilities and impose additional psychological pressure upon them.

008s: The mother tells me that the father was putting pressure on her. He thinks that she does not want to talk because she is frightened, so they were putting a lot of pressure on her from all areas to speak. It was difficult for her on top of the naming difficulties that she has.

0016s: He was putting him under pressure without noticing, to a degree that the patient does not prefer his father be present with him in the session, it is ok if his brother was present with him or anyone of his siblings, except his father, he feels ‘under stress’.

The SLT (0016s) attributed the father’s high expectations to his educational level and believe that his son can achieve more.

0016s: But still supporting, the father I mean, sometimes when someone is educated, how much educated he is; because he knows a lot, he doesn’t accept. He becomes like “he can do more, I know he can”, so it is not always the non-educated, sometimes we face issues with educated people because they are educated.

Moreover, rejecting an SLT’s therapy plan and not being convinced by therapeutic goals might put PWA in a difficult situation as to whether to cooperate and accept the SLT’s goals or agree with family members who have a different view. This situation could be confusing and distracting to PWA who have similar expectations to those of SLTs and aim to improve gradually.

0016s: If the family was agitated, they totally, would not accept the SLT's plan. They choose the plan; they interfere in the sessions, for example 'why do you do this for him, we do not want that, work with him on that thing', if that happens, this will distract the patient. The patient becomes upset and also do not know whether to listen to his family's advice or the SLT's advise. This situation makes problems to the patient, and we do not have the time for that; to put the patient in such a situation.

0016s: It becomes problematic if the family has goals and we have other goals, there will be confusion in the case.

6.7.2 Sub-theme 2: Managing expectations

Sub-theme 2 presents SLTs views on the methods they adopt to manage expectations of PWA and their families in aphasia therapy. SLTs mainly reconcile goals with PWA and their families, in addition to providing education in order to increase knowledge of stroke and aphasia.

6.7.2.1 Reconciling goals

Sometimes goals that are shared could be unrealistic as reported by 0021p and 0016s. When goals shared by PWA or families are unrealistic, SLTs reported reconciling goals to reach an agreement between triad members as in the following extracts.

0021s: Sometimes, some of the patients have high expectations, so we try to reconcile them.

0016s: Emm, some of the families have different goals, or for examples what is called non-realistic goals, so they must hear our goals and we hear their goals and reconcile them, and also, we explain to them the situation so that it become easier for the patient to achieve his goals.

From the viewpoint of 0026s, goals that are higher than PWA's current abilities can be incorporated as long-term goals.

0026s: To them, as a goal, they want her to be able to speak again, for the sake of that thing.
HA: For managing financial stuff again?
0026s: Exactly, because she was the one managing. Step by step, I mean sometimes they tell us that they want her speak, so that such and such, anyhow we started it step by step, I mean as a long-term goal.

6.7.2.2 PWA and family Education

SLTs reported providing education on the case to PWA and their families prior to therapy. Education on the case includes the meaning of stroke, changes in language-processing abilities, the prognosis, and the process of therapy to aware PWA and their families on the current level and the expected outcome. Such education on the case at initial stages aims at increasing the awareness of PWA and their families about the condition and also at managing their expectations as SLTs reported. Providing education to PWA and their families at initial stages of therapy was reported by 005s, 008s, and 0015s.

005s: Of course in the cases of aphasia, it must be that his comprehension abilities, it must be that he is aware of what has happened to him and what are the changes that has happened, whether it was simple, in other words it is possible that his situation can get back to what it was before, or the stroke is sever and the effects are long lasting. The patient and his family must know whether the changes are temporary or long-term and what are the consequences of it on the speech level, the language and the daily life in relation to his family or to the nature of his work.

008s: After the initial assessment, we sit with the family, we tell them the diagnosis, we explain to them what is expressive aphasia and what are the things that we expect from them if they are going to accompany the patient while he is in here, or in the outpatient sessions if they are going to come with the patient. We listen to their questions or queries; we give them a basic overview of the prognosis and the required things from them.

0015s: Some of the families do not know, so it is necessary that we explain to them what aphasia is to start with. They respond with ‘ok, it is enough if he becomes able to communicate to us his needs’; this is what the families mostly ask for when they comprehend the situation, ‘we want that he can communicate his wants and needs, this is the most important thing’.

0015s reported that education on the case was necessary in reaching an agreement on therapeutic goals and expectations.

0015s: It was not I mean, but they were telling us, we want his speech improves. I asked them what are the goals, it was like that ‘he speaks well’. They were not, but when I explained to them what his case was, they said, ‘yes, when he gets stuck in a speech, notice when he chats with us and not able to find the word, he goes silent and become upset’. I told them, yes, these are the things that we are working on, so they agreed, they said this is exactly what we want. Also, few members told me that, when he uses description in the conversation, it benefited him and them. It benefited them to understand what he wants to say.

When unmatched expectations appear in therapy, negative consequences could be present as reported in the previous sub-theme. Therefore, SLTs make an effort to resolve an issue and try to narrow the views between PWA, families and themselves. 0016s, 008s and 0015s used education to facilitate a greater understanding of stroke, aphasia and the appropriate goals for PWA.

0016s: I am planning to perform partner communication training, and education on the case and how he should treat his son, I mean in general, and that his son is not young, and this is how much it affecting his personality and psychological state. There will be partner communication training with the father, God willing.

008s: The mother tells me that the father was putting pressure on her. He thinks that she does not want to talk because she is frightened, so they were putting a lot of pressure on her from all areas to speak. It was difficult for her on top of the naming difficulties that she has. When we started and explained to the them the process, they agreed with me and they got how to communicate with her, so we started with her on single words.

0015s: More education to the families, and they must do the same things that we do, I mean the goals that we follow here must be followed at home too with him.

Self-awareness was a strategy used by 0015s to make her patient with aphasia aware of his current abilities, thus becoming convinced by the therapeutic goals. The SLT used an audio recorder to record the conversation of her patient with aphasia and use it in education.

0015s: When he came in, at the beginning, he felt that he is unable to speak, I mean he had what is called, low self-esteem as he was comparing himself to pre-stroke state. I explained and gave him education about his situation, that his situation is milder than what he sees. I mean, he feels he is not able to speak; so, onetime, we tried that he tells a story, and I let him record himself. When he heard himself, he like realised that it is ‘no, I can speak well’. He always needs encouragement; so, his goals have changed when he realised, when he heard himself, he said ‘yes, sometimes I get stuck in words’. He understood where the problem lies, unlike the first two sessions where he thought he was not speaking, so he needs like encouragement all day.

In some cases, and when SLTs encounter some challenges in narrowing the gap between different expectations, a family conference might be conducted. A family conference is a method reported by an SLT in SBAHC in which the rehabilitation team meet with the family in order to discuss the case, the roles of different healthcare providers, the goals and the rationales behind setting these goals.

0016s: We tell the physician that the family, for example, their performance was such and such in more than one session. If that requires a family conference, the physician is the one to decide. They do the family conference where the whole team, not just the SLT, but the SLT, the OT, the physician, the nurses and the case manager; we meet, all of us, with the family for an hour in a certain day. The discussion would be about the case in general, and what are our goals, and we as a facility, what is our role and what we must provide and why we chose these goals, and reconcile our goals with their goals, I mean we come out with an agreement, God willing.

SLTs' data show that when families have higher expectations, PWA might match expectations with SLTs. Education on the case and explicit discussions that SLTs conduct with families, aiming to minimise the gaps in expectations, are appreciated by the person with aphasia as in the extract below.

0016s: When I explain to the father, in front of the patient, for example, I tell him 'no, he needs time, he needs such and such', the patient goes 'yes'. He tells his father 'yes, it is true I need time, why are you putting pressure on me'; so it means, the patient is on our side when it comes to goals.

6.7.3 Theme five summary

Within theme five, participants' views on their expectations in aphasia therapy were revealed. Matched and unmatched expectations of PWA and their families were present in aphasia therapy. SLTs reported managing expectations by mainly reconciling goals with PWA and their families, and also by increasing their knowledge of stroke and aphasia.

Matched expectations were reported by participants groups, and SLTs expressed that an effective participation in discussions about therapeutic goals can lead to match expectations in aphasia therapy. In SLTs' views, this ultimately facilitates cooperation and motivation of PWA and their families in therapy .

Some PWA and family members can share unrealistic goals and have high expectations. When unmatched expectations were present in aphasia therapy, SLTs reported observing negative influence. From SLT’s views, these unmatched expectations were mainly expressed by family members which influenced motivation, cooperation, flow of therapy, and PWA psychological state.

To manage expectations in aphasia therapy, SLTs reconciling goals with PWA and their families, and incorporating high-level goals as long-term goals. They also reported increasing knowledge on the case through education, self-awareness, and conducting a team meeting.

6.8 Theme six: The nature of goals in aphasia therapy

Theme six presents the nature of goals in aphasia therapy in the Saudi context. Theme six presents goals for PWA, and also goals for their family members in aphasia therapy from participants views. In addition to participants’ views, SLTs goals that were documented in PWA’s case records contribute to this theme. The details of theme six are as follows:

- Sub-theme 1: Goals for PWA.

- General well-being goals.
- Impairment-based goals.
- Activity-related goals.
- Effective communication goals.
- Social participation goals.
- Service-related goals.

- Sub-theme2: Goals for family members.

- Education and strategies to support PWA.
- Home exercises.

A detailed structure of theme six, which illustrates results and contributing views, is presented below in Figure 6.15.

6.8.1 Sub-theme 1: Goals for PWA

Within sub-theme 1, participants expressed their views in relation to goals for PWA in speech and language therapy. Participants reported general well-being, impairment based, communication and relationships, social participation, and service-related goals.

6.8.1.1 General well-being goals

PWA expressed general goals reflecting their desire of being well and healthy after they experienced illness.

HA: I mean, when you were ill, what were you thinking of and what did you want?
003p: To be well, there were things for the first time in my life.

009p: I wished for nothing except that God gives me wellness.

Family members of PWA also reported goals that are general and related to well-being. Some family members expressed that they want their loved ones with aphasia to return to pre-stroke status.

0030f: By God, I have a fervent will to go back like he was before.

0012f: My goals that he goas back as he used to be as soon as possible. This matter of course in God’s hands and then the therapists.

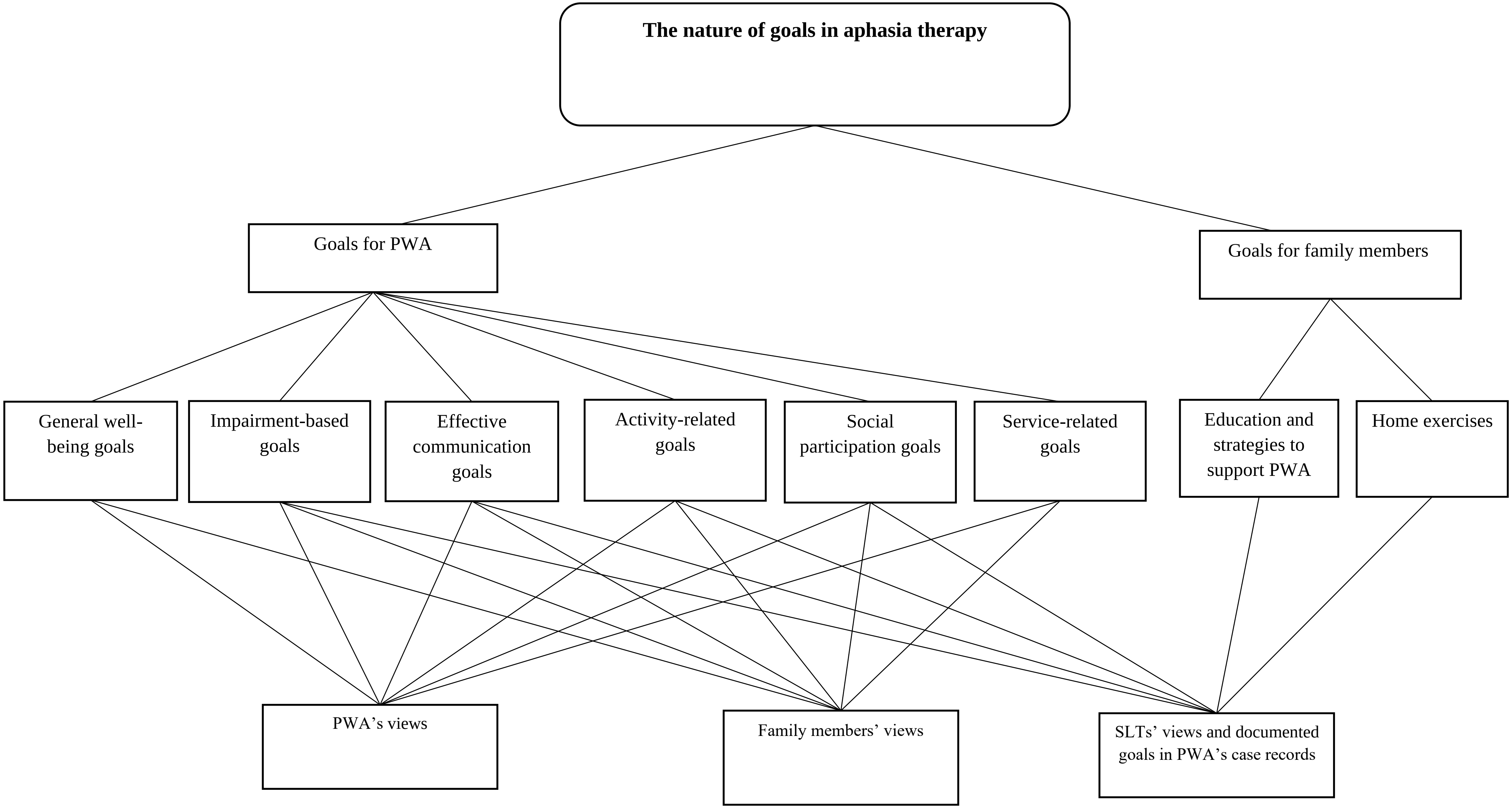


Figure 6.13 Theme six details and contributing views

0012f: My goals, honestly, I was really worried, I want him to go back as he used to be.

6.8.1.2 Impairment-based goals

In relation to impairment-based goals which mainly focus on targeting language processing in aphasia therapy, some PWA reported goals of finding words, understanding simple sentences and commands, in addition to generally improving language processing. As in the extract below, 009p expressed that he wants to correct what he is saying reflecting his goal to work on improving language processing.

HA: What do you hope to do better, but did not in this period?
009p: The speech that I am saying; I want to correct.

Family members of PWA also reported impairment-based goals for PWA including fluent and effortless speech, in addition to being brave. As in the extract below, 0018f reported that he wants his wife to be more fluent and to decrease linguistic errors that she produces.

0018f: The goal is speed and fluency and this is truly is difficult. More speed means errors which can lead to confusion between the masculine and the feminine pronouns so as to replace one for the other and vice versa. Also, confusion can happen in the address, locations, people, and individuals. That’s why if I quickly tried to do exercises hastily, there would be errors which can be readily alleviated by returning to [inaudible segment].

In the extracts below, 0023f and 0025f reported that they want their mothers to have effortless speaking abilities.

0023f: For speaking to be easy for her because sometimes she keeps crying, gets irritated and lose her ability to produce utterances as it is difficult for her to speak.

0025f: That she can pronounce like before or better, I mean she was a good speaker, I mean fluent. That was our ambition to go back as she used to be, and thanks to God there is an improvement I mean 80%.

0023f and 007f expressed that they want their loved ones with aphasia to challenge themselves and be braver.

0023f: I wish if she can challenge herself and reach a very high stage.

007f: I want to empower her; she could live her life with no one around her; I want her to be strong.

Most SLT’s reported impairment-based goals for PWA which they target in aphasia therapy. These goals include naming, completing sentences, improving intelligibility answering yes/no questions, and following commands. As in the extracts below, SLTs reported working on production by naming and completing sentences with PWA in aphasia therapy.

0026s: Concerning the 0027p, first thing, I would fulfil the same goals that already exist because they have been recently set since around a month. Therefore, the naming of uncommon verbs, uncommon nouns, combining them into sentences, this is a new harder goal set for her because the first was something simple and common. Now, it’s time to take her to a new challenging level.

Goal extract form 0013p’s case record:
-Improve naming skills, at basic functional needs; using picture cards of common nouns and semantic feature analysis.

Goal extract form 006p’s case record
-To improve patient's naming skills:
She will spontaneously name 20 items (10 in each category: food and clothes) with 80% accuracy, in 20 stimuli. At baseline, patient performed with 20% accuracy and after training, she scored 90% accuracy.

Goal extract form 009p's case record
-Circumlocution-induced naming (CIN) treatment
-Semantic feature analysis treatment.
-Improve naming skills (generative, divergent, convergent naming).

In addition to naming and completing sentences, The SLTs working with 003p reported that intelligibility is targeted in aphasia therapy.

Goal extract form 003p's case record
-Patient will improve his speech intelligibility at the word/phrase level by using the following techniques: exaggeration of words, and segmenting words in phrases with 70% accuracy with minimal cues.
-Patient will increase his vocal loudness at the conversation level when given verbal reminders.

Moreover, SLTs reported goals to improve language processing in relation to comprehension by working with PWA on answering yes/no questions and following commands.

0016s: My goals were that to work on basics; on the cognition and the attention, increase the attention. In relation to language, it was receptive language, identifying objects and pictures. In relation to auditory comprehension, it was answering verbally because he was expressing verbally and by gesturing, so my goal was to be answer yes/no question 100% verbally and follow simple command of one and two steps.

Goal extract form 006p's case record
-To improve auditory comprehension, patient will follow 3 simple and complex commands with 100% in 5 stimuli, within 6 weeks.

Goal extract form 003p's case record
-Patient will answer yes/no personal questions with 80% accuracy with moderate cues.
-Patient will follow 1-2step commands with 80% with minimal cues.

6.8.1.3 Activity-related goals

Some PWA reported goals of reading, writing, and reciting the Quran. In the following extracts, PWA expressed their goals in aphasia therapy which are related to reciting the Quran.

HA: Is there other things you wanted?
0029p: This.
HA: Communication?
0029p: Yes, (XXX) Quran
HA: The Quran, to practice it.
0029p: Yes.

0024p: I told her I could not read the Quran or to think about it my mind, like an illiterate person who cannot read. This is what has happened in my brain; I cannot read or even speak.
HA: You suggested the Quran to her so that you practice reading and become better.
0024p: Yes.

Some family members of PWA expressed goals related to reading, reciting the Quran and performing prayers. In the extract below, 004f expressed that he informed the SLT to work with his father on religious activity goals.

004f: Honestly, I have suggested, at the beginning of the week, that there should be more focus on the religious aspect, because he has forgotten the religious matters totally, be it the Quran verses or how to perform the prayer; so I told them to focus on the religious aspects a little bit.

0030f reported that she wants her husbands with aphasia to improve in reading.

0030f: I, thanks to God, I mean speaking is a little better I mean thanks to God, but reading is still.

Religious activity goals were reported by some SLTs. In the extract below, 0026s expressed working on reciting the Quran with 0024p as she requested that.

0026s: The Quran, because she said she wanted to work on such and such and such, but this is later on.

In the extract below, the Quran was targeted also in 0029p’s case as the SLT documented in his case record.

Goal extract form 0029p’s case record

-Patient will improve his automatic speech (Al-Fatiha, Al-Ekhlas and Al-Nas) with 100% accuracy without given prompts.

Moreover, SLTs reported working on reading with PWA as in the following extracts.

Goal extract form 0019p’s case record

-Syllabification technique.

-Oral reading drill at sentence level.

Goal extract form 0022p’s case record

-To improve patient's oral reading and reading comprehension, she was trained on following tasks:

- She will orally read given long sentences' questions that included variably complex vocabulary and answer them. After training, patient performed with an average of 80% accuracy, in 10 questions. She answered questions with 100% accuracy.
- She will orally read long paragraph included story and answer related questions.

In relation to writing goals, SLTs reported working on writing in addition to texting on the mobile phone as in the extracts below.

Goal extract form 006p’s case record

-To improve patient's writing skills, she will write the above 2-word utterances (verb + noun) with 60% accuracy, in 20 stimuli. At baseline, patient performed with 20% accuracy and after training, she scored 80% accuracy with minimal cues.

0026s: I have started mainly to focus on the area of writing. It was the last set goal for her; so, to improve her texting using mobile phone was my big last focus, that’s all concerning 0024p.

6.8.1.4 Effective communication goals

In relation to effective communication, PWA reported goals of joining a conversation, expressing, telling stories, speaking clearly on the phone, being understood by family, friends and other people. PWA in the extracts below expressed that speaking and expressing is what they wanted when they had stroke reflecting their goals at early stages of stroke occurrence.

HA: When you had stroke, what did you want and hope in general and in communication?
006p: To speak.

0024p: I wanted to express and tell them what I, what I, what.
HA: What do you feel?
0024p: Yes.
HA: Is that what you hoped for?
0024p: Yes.

HA: What did you want or hope when you first had stroke?
0022p: I wanted to speak to my kids, I wanted people to hear me, I wanted [pause] I was tired I was tired.

For their loved ones with aphasia, family members expressed goals including speaking, communicating effectively, and reading. 0010f and 0014f reported that speaking and expressing is important as in the extracts below.

0010f: I hope, it is just speaking and his hands.

0014f: We wanted, the walking, I mean walking and mobility are good now as before.
HA: Yes.
0014f: But speaking now.

007f attributed the importance of speaking to bonding time she has with her daughter.

007p: Speaking, I want speaking because when I talk with her.

004f, 0012f, and 0030f expressed that they want their loved ones with aphasia to communicate by speaking and not by using other alternative methods. This reflects that communicating by using alternative methods might not be desirable by family members even if needed.

004f: Of course, I want him to improve gradually, at least knowing the basics that he usually asks for like “I want to go to the toilet”, “I want to change my clothes” basic stuff at least.
HA: To request them by any means or speaking?
004f: By speaking.

0012f: He must speak and produce the word as he can because he always relies on writing or gesturing and this is not good for him.
HA: You want him to speak and not to depend on writing?
Yes, Yes, to not depend on gesturing or.

0030f: We desired that he speaks, we wanted him to speak. Frankly speaking, we don’t want devices

0025f expressed that an effective communication of her mother is important to reduce the psychological pressure on her.

0025s: My goals are that she can express what she wants; how we reach the information and what she wants for example, so that communication with her becomes easier with no difficulties for her, and not psychologically stressful for her.

For PWA, SLTs reported working on effective communication in conversations, using alternative methods of communication, reading, writing and texting. In the extracts below, SLTs reported working on effective communication and verbal expressions at a conversational level with PWA.

008s: Then we moved to describing an event using a connected two sentences of three-four words. After that, we started on a conversational level, and to answer open ended questions.

Goal extract form 009p’s case record:

-Improve patient expressive language skills to be able to communicate effectively to different conversational partners and participate socially in functional living environment.

-PACE technique to increase communicative effectiveness.

Goal extract form 006p’s case record

-To improve patient's verbal skills at conversational level, she was trained on re-telling the above stories verbally by using short sentences. From a baseline of producing 4-word utterances, patient produced an average of 6-word utterances with correct semantic and syntax features.

Goal extract form 0017p’s case record

-To improve patient's verbal expression, she will produce sentences of 3-4 words, with 100% accuracy, within 4 weeks

-The patient will be trained to initiate conversations and calling her own self.

Goal extract form 0024p’s case record

-The patient will be able to communicate using 2 -3-word utterances at conversation level with 60% accuracy, in 10 stimuli.

For PWA, SLTs reported setting goals related to using alternative methods of communication.

0026s: At first, the goals were to improve communication with her family. My view at the beginning was to start with the yes/no questions method using the basic AAC.

Goal extract form 0011p’s case record:

-The patient will utilize the app. Alexicom AAC, and pt. will be able to select or activate the desired message with fewer than 5 miss-hit, navigate between multiple pages and use function keys/buttons (e.g., speak all, clear) appropriately.

6.8.1.5 Social participation goals

In relation to participation within the wider social context, some PWA reported goals of speaking to people they don’t know, going back to university and completing their education, and also finding a job. As in the extract below, 0022p expressed that completing her university education is a goal for her, and 006p expressed also completing her education and also finding a job.

0022p: Before I had had stroke, I would have liked to help myself and my children. I wish now, with God allowance, to complete university education.
HA: Going back to university?
0022p: God willing.

006p: My education.
HA: Your education, great, to go back and continue.
006p: Yes.
HA: What else?
006p: And to get a job.

For their loved ones with aphasia in in relation to participation in the wider social context, family members reported goals of going back to work and socialising with strangers with no fear. In the extracts below, 007f expressed that she wants her daughter to find a job, and 0014 reported that she wants her husband to be independent again and return to his work.

007f: To work, I hope she get a job, but she doesn’t want to.

0014f: I mean I hope he get back to work, walk I mean, talk, and eats by himself I mean

0025f expressed that she wants her mother to go out more and socialise more with strangers, for example people she encounters in the gym.

0025f: I hope that I see her making more connections with people. I always tell he I get happy when I know that she is going outside or if she is invited, you know what I mean? I become happy because I want her to go out, she withdrew because she is scared to interact with people because of her speech. I feel that she is ok that there is no problem with her.

0025f: Now, I hope that she would be as bold as to emerge herself with people. People are so kind that those who even do not know her welcome her existence and her speech style. All I wish is that she is take a little courage to meet people outside like those in the gym.

SLTs goals for PWA in the participation domain are limited. One SLT expressed working on academic skills with the stroke survivor with aphasia to facilitate going back to university.

008s: When she was here as outpatient, I worked on oral reading, writing at a paragraph level; we worked on that for a period then I worked with her on academic skills.

The SLT also reported that she targeted social participation in aphasia therapy by working on scenarios that reflects real life situations.

008s: Last time, I worked with her on a scenario where she is going to a cafe or a beauty salon. After that, we made it more difficult, if she was the beauty salon owner, how would she service her customers.

6.8.1.6 Service-related goals

Few PWA and family members reported goals related to aphasia services. Some PWA reported that they wanted to know more about aphasia. As in the extract below, 0017p expressed that she wanted more information about what happened to her when she had stroke reflecting that information provision is desired by PWA at early stages of therapy.

HA: What you first wanted when you woke up and found that you had a stroke?
0017p: Why I had a stroke, why I had no knowledge, and the causes that; but thanks to God.
HA: Did you want to know the causes?
0017p: Yes.

For their loved ones with aphasia, some family members reported goals related to further services. 0023f, expressed she wants an intensive treatment for her mother, while 0012f expressed that he wants to seek a more advanced treatment abroad in Germany.

0023f: She may need very intensive treatment sessions.

0012f: Yes of course I have goals, which is, of course, goals and opinions from the closest relatives, it is [inaudible segment] to go abroad; these are part of our aim. There are people who advised me and other people did not advise me, especially about Germany; I heard that the treatment is more advanced there, I mean developed much more than the Arabic region.

The Venn diagram below (Figure 6.14) illustrates the views of participants on their goals for PWA in aphasia therapy.

6.8.2 Sub-theme 2: Goals for family members

Within this sub-theme, SLTs reported their goals in aphasia therapy for family members of PWA. SLTs goals for family members are mainly focused on supporting PWA. SLTs goals included education on the case and supporting the communication of PWA, in addition to providing home exercises.

6.8.2.1 Education and strategies to support PWA

SLTs expressed providing education to family members in order to increase their knowledge of stroke and aphasia as in the following extracts.

0016s: There are two things. At first, I would educate him on the case, and I would train him how to communicate with the patient. That’s because he can get mad because the patient does not answer him, so he needs to be trained how to communicate with the patient as should be.

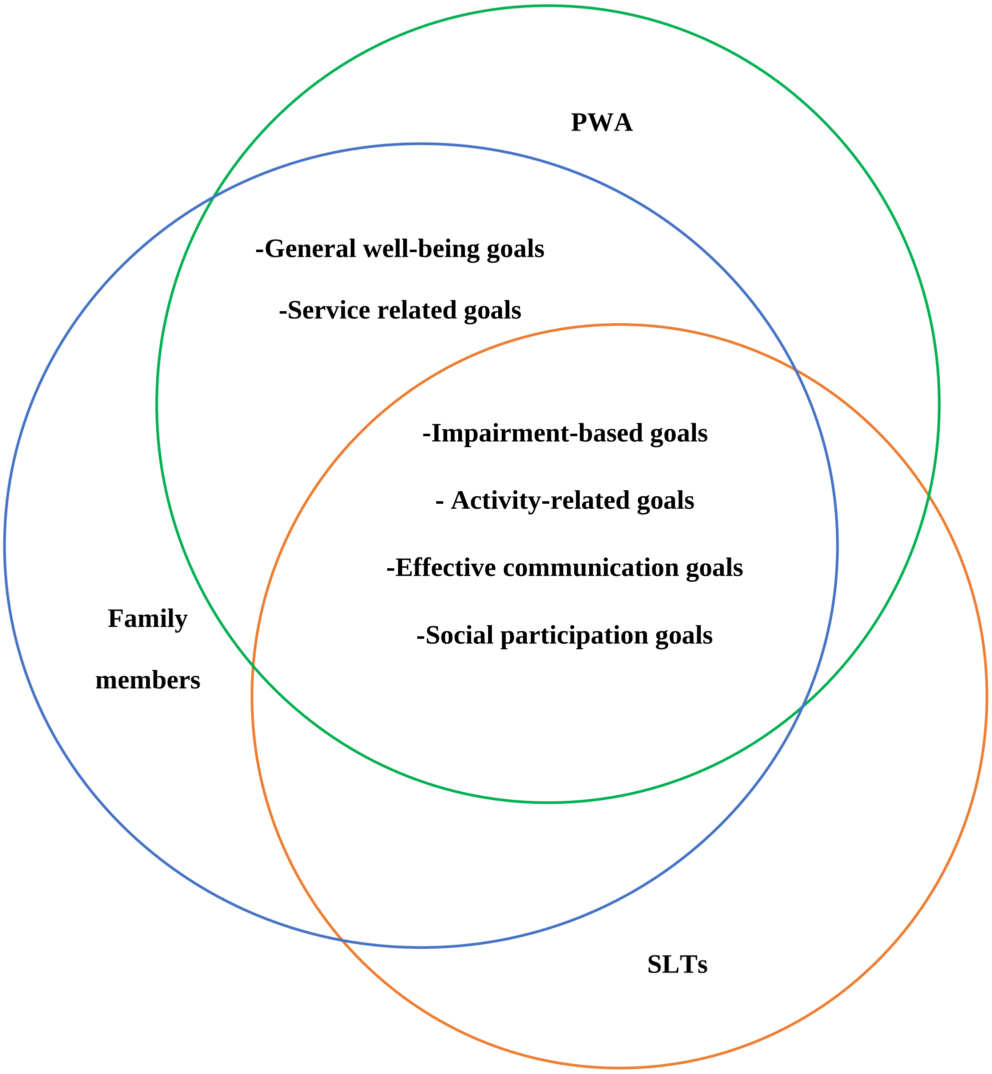


Figure 6.14 Goals for PWA in aphasia therapy

005s: As far as the children are concerned, we tried to educate them about their father's health case so that they could handle him correctly whether in the hospital or whether at home for a period of time after discharge.

Goal extract form 0017p's case record

-Discuss the family support and education with her husband.

Goal extract form 0011's case record

Patient family education.

To support the communication of PWA, SLTs reported providing strategies for the family members of PWA to handle challenges during conversations and communication. 0015s expressed that she trained the conversation partner of 009p (the family member) to facilitate the conversation and help the person with aphasia when encountering word finding difficulties.

0015s: Yes, they should learn how to handle with the conversation they initiate with him. For example, when their patient gets stuck in conversation, they should not readily dictate to him the word he forgot. They should, instead of that, let him speak as the mode takes him and describe whatever he wants. They should help their father get at the meaning and utterance he craved for. They have to understand the problem that he has. He would not get better if every time he got stuck on some utterances, they would immediately produce them for him. There should be more education directed to the patient's family and they have to work on the same goals that we set her in therapy.

0015s: We worked also on circumlocution where he goes around the word description until he produces it or that the partner helps after describing, so 009p doesn't feel stuck or that he cannot complete the conversation or the story.

SLTs in the following extracts also reported giving family members strategies to support the communication of PWA during conversations.

005s: Of course, family members participate in many activities. They can get involved in the activities or learn from us how they deal with the patient in the case of stroke. For example, giving the patients the sufficient time to speak, not trying to get complicated reply from him/her, facilitating the messages to be intelligible to him/her and not to interrupt the continuity of speech if she/he wants to tell something.

008s: I gave her how to encourage her to respond to open ended questions and initiate conversation, so when they go out, she initiates the conversation; also, how to encourage her to read and write.

Goal extract form 0029p’s case record:

-Patient's family will demonstrate understanding of using communicative strategies to support patient with his speech and language skills.

6.8.2.2 Home exercises

Some SLTs reported giving home exercises to family members. As in the following extracts, SLTs expressed providing home exercises in order to continue working on therapeutic goals at home.

0021s: I contacted his wife because she was not accompanying him here, so we contacted her and asked her if she can attend once a week to explain our goals and how to communicate with him. I explained all that to her, so that at the end of each week, I give her like a home exercise to work with him at home, and then ask her to tell us what happened; this is what we started with.

0031s: I mostly make, specifically his wife to be enrolled in the session, I mean to work with him at home on the things I work with him in therapy.

0026f: The goals were, I mean to apply what we do in sessions at home, so they were cooperative, I mean her family worked on verbal production.

0016 in the following extract reported that family members practice therapeutic activities, which were provided by SLTs, with PWA in order to achieve the intended goals as reported in the following extract.

0016s: His brothers support and encourage him. They even tried to apply the training and techniques I had been giving him in the room and other places when they accompanied him in his first admission.

6.8.3 Theme six summary

Within theme six, participants' views on their goals in aphasia therapy were revealed. All participants reported goals for PWA, and SLTs reported goals for their family members in aphasia therapy.

For PWA, participants expressed general wellbeing, impairment-based, Activity-related, effective communication, social participation, and service-related goals. Impairment-based goals reported by participants included language processing, naming, completing sentences, answering yes/no questions, following commands, intelligibility and fluency goals. Activity-related goals were reported by some PWA and their families including reading, writing and religious activity goals. In relation to communication, goals related to effective communication in conversations and with family and friends were reported. SLTs reported using alternative methods of communication with PWA. Some family members expressed that their goal for PWA is to speak and not using alternative methods of communication which reflects their rejection to such methods. Their rejection of alternative methods can be related to how people using alternative methods of communication are perceived in the culture. Regarding social participation, participants reported goals to increase participation in the wider society including gaining an educational degree, getting a job, and socialising without fear (participation goals). However, participation goals were less targeted in aphasia therapy as only one SLT reported goals of academic skills and socialising. In relation to service-related factors, some PWA and family members reported that they want to know more about stroke and aphasia and their desire for further intensive and advanced treatments.

Regarding goals for family members of PWA in aphasia therapy, SLTs expressed setting goals that target supporting the communication of PWA. SLTs provided education on the case to family members, in addition to strategies to support the communication of PWA. Some SLTs also expressed giving family member home exercises to work with PWA on therapeutic goals at their homes.

6.9 Chapter summary

The data analysis identified six main themes derived from the interviews and the case note data. The results include six major themes, namely: Stroke occurrence and the social context, The impact of stroke and aphasia, Identifying therapeutic goals, Participation in goal-setting, Expectations in aphasia therapy, and The nature of goals in aphasia therapy. Each theme contains sub-themes where views from the three participant groups (PWA, family members, and SLTs) were presented, and rich extracts of participant's responses were provided.

The results suggest that PWA and their families went through sudden life changes; PWA and their families experienced a sudden occurrence and confusion as well. Family members went through challenges related to managing a new medical condition and also related to communicating with their loved ones with aphasia. PWA and their families reported depending on God and being proactive in addition to patience to cope with the new life changes that are related to stroke and aphasia. PWA and their families encountered people in the Saudi society who are not aware enough about stroke and aphasia as they provided improper informal recommendations or did not communicate properly with PWA. Both PWA and their families reported that awareness is needed among society in relation to stroke and aphasia.

Stroke and aphasia impacted both PWA and their families as reported by them. Stroke and aphasia affected PWA's physical abilities and daily activities including religious activities. Moreover, stroke and aphasia affected PWA's communication skills, social participation, and psychological well-being. In relation to the family members of PWA, Stroke and aphasia also impacted their lives in which social participation and their psychological well-being became affected. The occurrence of stroke and aphasia caused changes in family dynamics as reported by participants. A negative influence on marital relationships and a positive influence on family bonding was reported by PWA and their families. Moreover, family member reported providing their support to their family members affected by stroke and aphasia.

In aphasia therapy and when identifying therapeutic goals for PWA, SLTs take into consideration the individuality of each case by setting goals according to PWA's abilities and functional needs. Moreover, SLTs take into consideration goal achievability by ensuring setting small and realistic steps to reach the final desired results. SLTs also reported involving PWA and their families in discussions about therapeutic goals.

In relation to the participation of PWA and their families in discussions about therapeutic goals in aphasia therapy, some participants reported sharing their personal goals including religious activity goals with their SLTs. Most PWA and family members reported trust in SLTs as health care professionals who possess the knowledge to set therapeutic goals in aphasia therapy; hence, they did not participate in the decision-making process. Factors related to effective participation in discussions about therapeutic goals in aphasia therapy were reported by participants. These factors include condition-related factors, knowledge of stroke and aphasia, family presence in therapy sessions, and service-related factors.

In aphasia therapy, participants reported the presence of matched and unmatched expectations. SLTs expressed that increased effective participation lead to matched expectations, which ultimately lead to motivation and cooperation. On the contrary, the presence of unmatched expectations poses negative impact on aphasia therapy including, pressure on PWA, disrupting therapy, and lack of motivation. To manage expectations in aphasia therapy, SLTs reported that they reconcile goals with PWA and their families, and that they provide education on the case to them.

All participant groups reported goals for PWA in aphasia therapy, and SLTs expressed goals for their family members as well. For PWA, goals were categorised under general well-being, impairment-based, activity-related, effective communication, social participation, and service-related. Family members expressed that they want their loved ones with aphasia to speak and not to use alternative methods of communication reflecting their rejection to these methods even if needed. SLTs reported goals for family members of which all are related to supporting PWA. SLTs goals for family members include education and providing strategies to support the communication of PWA, in addition to the provision of home exercises.

The following chapter 7 presents a discussion of findings in relation to the study context and other contexts reported in the literature, in addition to interrelating the findings of themes to conceptualise goal-setting within the context of experiencing stroke and aphasia in Saudi Arabia. Chapter 7 also presents research limitations, implications, and future directions.

Chapter 7 Discussion and conclusion

7.1 Introduction

Chapter 7 presents a discussion of the main results of the study. Research aim, a summary of findings, and discussion of findings in relation to studies reported in the literature are presented at first. Then, this chapter presents a conceptualisation of goal-setting in aphasia rehabilitation in the context of PWA's and families' experience of stroke and aphasia by interrelating findings of themes. This is followed by an argument surrounding the necessity of considering the cultural context in research and aphasia rehabilitation. The chapter concludes by presenting clinical and future implications, research contribution, strengths and limitations, and conclusion of the research.

7.2 Aims of the study and a summary of the findings

The current study aimed to explore therapeutic goal-setting in aphasia rehabilitation within the Saudi context of people's experience of stroke and aphasia. The experience of stroke and aphasia and the practice of goal-setting in aphasia rehabilitation has not been investigated previously in Saudi Arabia. The current study adds knowledge to the body of literature and provides a foundation for further investigations. The qualitative triadic analysis in this project, which involves comparing and interpreting the views of three groups (PWA, family members, and SLTs) is another novel element to aphasia research in the Saudi context. Moreover, exploring the cultural context of the experience of stroke and aphasia provided a new perspective into goal-setting in aphasia rehabilitation that was not reported previously in the literature. Such understanding of the cultural context when delivering aphasia services is needed to provide relevant and sensitive services to PWA and their families who come from different backgrounds.

Data analysis revealed six major themes that present findings related to the experience of stroke and aphasia and goal-setting in aphasia rehabilitation. Each theme contains sub-themes, in which results are presented from three viewpoints (PWA, their family members, and SLTs). The themes are as follows: Stroke occurrence and the social context, The impact of stroke and aphasia, Identifying therapeutic goals, Participation in goal-setting, Expectations in aphasia therapy, and The nature of goals in aphasia therapy. The results of themes are discussed below in relation to the literature, and a conceptualisation of goal-setting in Saudi aphasia rehabilitation is presented by interrelating the findings of themes.

Findings suggest that goal-setting in Saudi aphasia rehabilitation is highly context-based because of the presence of contextual factors that have a strong influence on the processes involved, i.e. beliefs and attitudes inherent in the Islamic faith, and factors associated with a collectivist system. The findings also suggest that goal-setting is informal and therapist-led in Saudi aphasia rehabilitation. The findings of this study emphasise the role of SLTs in empowering and supporting PWA and their family members in aphasia rehabilitation in a context-sensitive way. It is suggested that supporting the effective involvement of PWA and their family members in the process of goal-setting facilitates reaching matched expectations; thus, increasing motivation, cooperation, and commitment to aphasia therapy.

Within the framework of the thematic structure, the following section provides discussions of findings surrounding the wider literature and the Saudi context. Then, a conceptualisation of goal-setting in Saudi aphasia rehabilitation is presented by interrelating the findings of themes.

7.3 Discussion of research findings

7.3.1 Theme one: Stroke occurrence and the social context

The results of theme one show that stroke and aphasia cause sudden life changes in which PWA and their families experience confusion and challenges to manage the new health condition. Their coping with the new condition is facilitated by contextual cultural and factors including their religious faith, being proactive, and having patience when dealing with challenges. In relation to the social context of the experience, PWA and their families encountered people in the Saudi society who lack information about stroke and aphasia, and they expressed that increased society awareness is needed. Findings are discussed in detail below.

Research into exploring the experience of people after the occurrence of stroke has been widely conducted in English-speaking and Western countries (e.g. the UK, the USA, Canada, Sweden, Australia, and Italy), and it constitutes a substantial research literature. (e.g. Greenwood & Mackenzie, 2010; Hesamzadeh, Dalvandi, Bagher Maddah, Fallahi Khoshknab, & Ahmadi, 2015; Luker et al., 2017; Nasr et al., 2016; Simeone et al., 2015). In these studies however, PWA were either excluded or insufficient information was provided in relation to their inclusion (e.g. Kitson, Dow, Calabrese, Locock, & Athlin, 2013; Nasr et al., 2016; Simeone et al., 2015). As evidenced in the systematic reviews conducted by Luker et al. (2017), Martin-Saez and James (2019), and Lawrence (2010), limited researchers reported the inclusion of PWA explicitly in their studies. The current study adds to the body of knowledge by reporting the experience of stroke survivors with aphasia. The current study also provides a qualitative account of PWA's and families' experience with their condition in a context that is new to what has been reported in the literature previously.

In relation to constructing their own experience of stroke, PWA and their families in the current study reported that they experienced a sudden occurrence which they did not expect as no symptoms were observed. Other participants in the current study constructed their experience around the confusion that was present. Constructing the experience of stroke around a sudden, disruptive occurrence was reported previously in Sweden and the UK (Banks & Pearson, 2004; Bendz, 2003; Immenschuh, 2005; Nasr et al., 2016). Participants in the current study reported that confusion was present mainly because they were undergoing stroke and unable to identify that what they were experiencing were symptoms of stroke. Moreover, confusion was present because of some ambiguity that participants faced when they were diagnosed with acute stroke. The confusion that PWA and family member experienced while undergoing stroke and treatment was related to the insufficient information provided to them by physicians as participants reported. It has been reported in the literature that stroke survivors and their carers need information on the nature of stroke (Hanger & Mulley, 1993; Hanger, Walker, Paterson, McBride, & Sainsbury, 1998). Thus, providing insufficient information at a critical acute phase could leave PWA and their families confused. A possible interpretation of the insufficient information participants reported receiving during the acute stroke diagnosis phase could be linked to the healthcare facility systems. It could be that the healthcare facility does not include a systematic procedure to follow in stroke cases, such as information provision that covers specific areas important to PWA and their families in the early stages (e.g. information about the possible impact of stroke and the available rehabilitation services). It is also possible that people's recall is poor due to stress, for example Shankar (2003) found that medical information memory might be poor when patients are stressed or old.

Family members in the current study expressed challenges encountered following diagnosis. These challenges were related to their new roles in managing a new medical condition of which they did not possess knowledge. The challenges were also related to the communication difficulties, which were a new element in their lives after the occurrence of stroke. The challenges encountered by family members are in line with what has been reported in the literature in relation to carers' new roles and responsibilities after stroke occurrence (e.g. Hesamzadeh et al., 2015; Lou et al., 2017; Winkler et al., 2014).

With regard to the experience of PWA and their family members in relation to the wider social context in Saudi Arabia, both groups reported that they have observed insufficient knowledge amongst society, as reflected in the informal recommendations given by friends and how people in society interact with PWA. Insufficient knowledge of stroke in general and its signs and symptoms in particular in Saudi society was reported by Alaqeel, AlAmmari, AlSyefi, Al-Hussain, and Mohammad (2017). The researchers concluded that there is a need for public awareness of stroke within the Saudi community, as they found a lack of knowledge in the areas of stroke risk factors (e.g. hypertension, diabetes mellitus, and tobacco smoking) and the signs and symptoms of stroke (e.g. speech difficulty, blurred vision, numbness, and dizziness). Such insufficient knowledge of stroke and aphasia in Saudi society could be attributed to the lack of appropriate means used to spread awareness, or to the fact that individuals only devote time to learning about the topic when someone whom they know experiences stroke. Alaqeel, AlAmmari, AlSyefi, Al-Hussain, and Mohammad (2017) suggested that in the future the use of novel methods, such as social media, for presenting stroke awareness campaigns is indicated. Insufficient knowledge of stroke in Saudi society was reported in the study of Al Khathaami, Mohammad, Alibrahim, and Jradi (2018), wherein the researchers investigated factors that are associated with the late arrival of individuals with acute stroke to hospitals. They found that insufficient knowledge of signs and symptoms was one of the critical factors. A number of studies in different countries, including Denmark, Ireland, and the UK, have found low levels of knowledge of stroke amongst society (Hickey, Holly, McGee, Conroy, & Shelley, 2012; Jones, Jenkinson, Leathley, & Watkins, 2009; Truelsen & Krarup, 2010).

Participants' views in this theme suggests that Islamic religious faith is a factor in the experience of stroke and aphasia. The following sub-section discuss Islam in Saudi Arabia and participants' attitudes towards stroke and aphasia.

7.3.1.1 Islam in Saudi Arabia and attitudes towards stroke and aphasia

Two Islamic holy cities are located in Saudi Arabia, i.e. Mecca and Madinah. Saudi Arabia is a country in which Islam is the established religion (Nyrop, 1993) and *sharia* law (derived from the *Quran* and *Hadith*) is the main source of legislation (Lewis, 2001; Vogel, 2012). The majority of individuals in Saudi Arabia are Sunni Muslims (Nyrop, 1993). Thus, Islamic faith is a central component of people's belief system and values in Saudi Arabia, and Islamic practices are a fundamental component of their daily lives.

In Islamic faith, Muslims are encouraged to practice an important principle called *Tawakkul.* In *Tawakkul*, Muslims practise increasing their faith in God by trusting God's plan, while also being proactive and seeking the means that lead to the desired outcome. By doing so, people believe that distress is decreased because they know that they were not passive, but that challenges are inevitable in life, and a higher power is in control. The principle of *Tawakkul* has been reported in medical rehabilitation literature, for example the adoption of this mindset by Muslims who undergo rehabilitation was reported by Yamey and Greenwood (2004), who investigated different religious views on rehabilitation. In their study, Muslims who were receiving rehabilitation services maintained their strong faith in God's will while seeking help, as this is what Islam promotes in the face of loss and challenges. Rassool (2000) and Yamey and Greenwood (2004) stated that Muslims viewed illnesses as being tests from God and an inevitable component of human life, yet seeking help is also part of their responsibilities, as the Prophet Muhammad stated: "Seek treatment, because Allah did not create a sickness but has created a treatment for it except for old age." With regard to coping with stroke and aphasia in Saudi culture, few studies have been carried out. Those which have been conducted did not report that Islamic faith was a factor present in PWA's experience. Al-jadaan (2014) hypothesised that this would be a factor in his study of Saudi PWA, but he reported that religious items were removed from his questionnaire because of lack of association of religious items to QoL of PWA. Al-jadaan (2014) attributed this finding to the fact that religion was examined through an inappropriate tool that focused on activities and duties which might led PWA to provide socially accepted answers to the questions asked. This indicate that such cultural issues are sensitive in the Saudi culture and should be examined carefully.

In relation to the current study, some PWA and their family members reported that religious beliefs helped them to cope, as they expressed that this situation had been prescribed for them by God. Evidence of the impact of Islamic religious faith upon stroke survivors' attitudes towards illness is limited in aphasia research, as the majority of studies in stroke or medical rehabilitation literature have reported populations with diverse religious faiths. Three studies were conducted in Italy, the USA, and Australia to explore the role religious faith in general after the occurrence of stroke but not specifically aphasia (Ch'ng, French, & McLean, 2008; Giaquinto, Spiridigliozzi, & Caracciolo, 2007; Robinson-Smith, 2002). In those reported studies, findings were similar to the current study in which religious faith facilitated coping after stroke occurrence.

Although PWA and families in the current study held religious belief in the inevitability of the occurrence of stroke and aphasia, they reported that they were not passive in handling their medical condition. PWA and their families expressed being proactive by seeking medical rehabilitation, using augmentative and alternative methods to communicate, the willingness to support other PWA, and self-dependence to improve communication skills. A possible interpretation of participants’ attitudes could be attributed to the principle of *Tawakkul* in Islamic faith.

In addition to Islamic faith as a factor present in the context of peoples’ experience in this study, the following sub-section discuss collectivism in Saudi Arabia and views on masculinity as reported by participants.

7.3.1.2 Stroke, aphasia and views on masculinity from a cultural perspective

Saudi Arabia is an Arab country and it is common in such countries for collectivism to be the norm rather than individualism (Buda & Elsayed-Alkhouly, 1998). In such cultures, the person is mostly defined by his/her family or social group, and actions are mainly guided by the group norm in the society (Triandis, McCusker, & Hui, 1990). Hierarchies are also seen in families such as the father being in control of all matters related to the family members (Triandis, McCusker, & Hui, 1990). Therefore, In Saudi culture, the man is perceived as the head of the family, provider, and decision maker in most cases.

In this study and within theme one, one person with aphasia and his wife commented on masculinity in relation to vulnerability after stroke. The person with aphasia linked his physical weakness to his masculinity as he focused on staying strong although he was going through the symptoms of stroke. The wife of this person with aphasia reported her experience of people questioning why a wife talks on behalf of her husband. A possible interpretation of those situations can be that vulnerability caused by stroke might compromise men's role and the way they are perceived by others in the society. Such views on masculinity and vulnerability can be related to the role of men in the Saudi culture which is considered a more collectivist culture in comparison to other Western countries.

The findings of theme one provide a perspective on PWA's and families' attitudes towards stroke and aphasia in a different new context to those studied prior to this, and identifies how the Islamic faith is part of the experience. The findings also revealed that PWA and their family members live in a collectivist culture where men's role and how they are perceived by others can be compromised by the occurrence of stroke. The findings also present how the knowledge of stroke and aphasia is generally insufficient amongst people in Saudi society

7.3.2 Theme two: The impact of stroke and aphasia

Stroke and aphasia heavily impact the lives of PWA and their families as participants reported. PWA's physical abilities and activities, communication skills, social participation and psychological well-being are affected. Family members' social participation and psychological well-being are also affected by stroke and aphasia. Changes in the family dynamics also occur after stroke and aphasia in which familial relationships are influenced. The changes in family dynamics is also seen in the care and support given to PWA by their family members.

In the current study, PWA, their family members, and SLTs reported aspects of lives that were highly affected by stroke and aphasia. All participant groups reported that stroke and aphasia affected the physical abilities, activities, and communication skills of PWA. Whilst the cultural impact of Islamic religious faith impacted on attitudes towards stroke, as reported in theme one, some participants also reported that, conversely, stroke and aphasia impacted on the practice of their Islamic religious faith. The difficulties that PWA encounter after the occurrence of stroke and aphasia hinder them in practising their religious routines as they used to prior to the occurrence of stroke. Some PWA and family members reported that reading the Quran and performing prayers after undergoing stroke were affected. Such impact on religious activities and the desire to reperform them was observed in other Asian countries where Islam is also the predominant religion. Norris, Allotey, and Barrett, (2012) reported that Indonesian stroke survivors in their study felt the obligation to reperform religious activities, and that it was a potential motivator during the rehabilitation process.

All participant groups reported that the psychological well-being of PWA was impacted, as they experienced different feelings of being a burden, missing life prior to the occurrence of stroke, anger, and being overwhelmed. Participants reported that PWA also experienced social withdrawal. These reported psychological and social negative impact on PWA are in line with what has been reported in both stroke literature and aphasia literature on English -speaking and Western countries (e.g. the UK and Australia) (Carod-Artal et al., 2000; Davidson et al., 2008; Fotiadou et al., 2014; Lawrence, 2010; Martin-Saez & James, 2019; Northcott et al., 2016; Susie Parr, 2001, 2007; Pike et al., 2017; Simeone et al., 2015). The negative impact of stroke and aphasia that affects different aspects of PWA's lives in the current study also mirrors the findings of a study that was conducted in Portugal (Matos, Maria Assunção CJesus & Cruice, 2014).

Family members in the current study reported that they experienced feelings of being overwhelmed, worry, default, apathy, guilt, and sympathy. In addition to that, one family member reported that her obligation to take care of her mother restricted her form pursuing her dreams of being employed. The presence of negative influence on family members of PWA in this study mirrors findings reported in the UK, the USA, Australia, and New Zealand (Grawburg, Howe, Worrall, & Scarinci, 2013a, 2013b, 2014, 2019; Threats, 2010; Winkler, Bedford, Northcott, & Hilari, 2014). The findings of the current study is also similar to what has been observed in Japan and Italy in families who are providing care to patients with Alzheimer's disease, dementia, and brain tumours as the researchers reported poorer quality of life in those families (Goren, Montgomery, Kahle-Wrobleski, Nakamura, & Ueda, 2016; Petruzzi, Finocchiaro, Lamperti, & Salmaggi, 2013).

Some PWA and family members reported experiencing changes in family dynamics, which was seen negatively in the marital status and positively in family bonding. Stroke and aphasia studies conducted in Canada, the UK, Australia, and New Zealand have reported similar results in relation to the positive impact on families and the negative impact on the marital status (Anderson et al., 2017; Grawburg et al., 2012, 2013a; Winkler et al., 2014).

Although family members in the current study reported that their lives have been negatively affected since the occurrence of stroke, they reported that they provide support to PWA in relation to the areas of their lives that have been affected. Family members reported providing support for PWA to undertake religious activities, which reflects the importance of religious practices in the Saudi Muslim context. Moreover, families reported providing social and emotional support to PWA. Support from families for a person with aphasia is evident in the literature, e.g. in Canada, the USA, and Australia (Boles, 2006; Brown, Worrall, Davidson, & Howe, 2011a & b; Code & Herrmann, 2003; Grawburg et al., 2014). However, family support in these studies was not discussed from a broader perspective such as cultural or religious predominance. The following sub-section discuss taking care of stroke survivors in a collectivist culture and where Islamic faith is the predominant religion.

7.3.2.1 Taking care of stroke survivors from a cultural perspective

The obligation to take care of a sick person in the family can be interpreted from a cultural perspective. The collectivist culture in Saudi Arabia stems from the structure of society which constitutes different tribes. In tribal societies like Saudi Arabia (Al-Dabbagh & Gargani, 2018), looking after tribal members and taking care of members who suffer from diseases are sources of pride and obligation (Sendiony, 1981). Furthermore, the elderly in Saudi families are respected and taken care of so as to reflect a rooted traditional tribal value, as well as to show appreciation for elders’ valuable effort and their support to the younger members over the years. Since the Saudi culture is more collectivist in comparison to other Western cultures, some people live in extended families in which two generations of adults could share the same household. For example, the stroke survivor could be an elder living in an extended family in which his/her house becomes the main household in which unmarried daughters, unmarried sons, married sons and their small families live together. Therefore, sons and daughters take care of the elderly with stroke and aphasia.

A difference can be observed between the Western research literature describing the experience of stroke and aphasia and the Saudi context described in the current study in respect of the level of familial involvement. In this study, spouses were involved in five triads, while mothers/fathers or sons/daughters were involved in the remaining six, whereas in western research literature the majority of caregivers participating in studies constitute spouses of a person suffering from stroke (Ferguson et al., 2010; Grawburg et al., 2013b; Greenwood & Mackenzie, 2010). A generalisation with regard to the family member group which is mostly involved in taking care of stroke survivors in the Saudi context is difficult to make due to the number of participant triads in the current study, and also because there is no other study in the Saudi context discussing the involvement of families in taking care of stroke survivors who suffer from aphasia. A possible interpretation can be related to the family structure in Saudi culture. For example, mothers/fathers or sons/daughters could become involved in taking care of stroke survivors because unmarried sons and daughters live in the same household with their parents until they get married.

Taking care of elders in the family can also be interpreted from the perspective of Islam, the predominant religion in Saudi Arabia. In Islam, parents and elders possess high value. Taking care of parents and the elderly in the family is a noble duty that is promoted by Islamic values (Sendiony, 1981; Yamey & Greenwood, 2004). Parents were mentioned in the Quran several times with appreciation and respect. In appreciation of their great role in their children's lives, respecting parents is second only to worshipping Allah. Allah Almighty states in a verse of the Holy Quran: "Worship Allah and join none with Him in worship, and do good to parents" (Quran, 4:36). In another verse, devotion to and respect for old parents are stressed; Allah Almighty states: "Your Lord has decreed that you worship none but Him and that you be kind to parents. Whether one or both of them attain old age in your life, say not to them a word of contempt, nor repel them, but address them in terms of honor" (Quran, 17:23). Young children in Saudi culture are raised with these principles being taught in families and schools. Children are always encouraged to respect the elderly and obey their parents. As children grow up and parents become old, children assume responsibilities and take care of their parents so as to show their appreciation and respect.

The obligation to take care of family members who are recovering from stroke has also been reported in the literature in other cultures. Similar to the current study, the obligation to take care of stroke survivors stems from religious beliefs and cultural values in the British Indian and Hispanic cultures (Katbamna, Manning, Mistri, Johnson, & Robinson, 2017; Torregosa, Sada, & Perez, 2018).

Findings of theme two suggest that stroke and aphasia heavily impact PWA's and their families' lives. Although the impact of stroke and aphasia as reported by Saudi individuals is similar to what has been reported previously in the literature in western countries, this study presents a cultural context that is new to what is reported in the literature. This study provides a qualitative account of the impact of stroke and aphasia upon religious practices, since Islamic faith is a central aspect of the Saudi context. Moreover, the study provides a cultural perspective on the obligation of taking care of PWA.

7.3.3 Theme three: Identifying therapeutic goals

In the current study, SLTs reported identifying therapeutic goals based on the individuality of the case by considering abilities and functional needs, and also achievability of goals by considering taking small realistic steps. They reported that they involved PWA and their families in discussions surrounding therapeutic goals.

In medical rehabilitation literature, there is no consensus on how goals should be identified, or on the best goal-setting approach in clinical practice (Leach, Cornwell, Fleming, & Haines, 2010; Playford, Siegert, Levack, & Freeman, 2009). Thus, drawing conclusions in relation to the best practice in aphasia rehabilitation can be challenging. In relation to goal-setting recommendations in aphasia/rehabilitation literature, the identification of areas that need changes, in addition to the specific actions that should be undertaken to achieve goals, has been reported (Hersh, Worrall, et al., 2012; Schut & Stam, 1994; Wade, 1999, 2009). These aspects are reflected in the current study, in which SLTs identified goals according to PWA’s strengths and weaknesses and functional needs, and assigned attainable small steps with which to achieve the intended goals. Recommendations in the literature encourage addressing goals that are important to PWA and their families (Schut & Stam, 1994; Wade, 1999, 2009), which is also reflected in this study, as SLTs reported discussing therapeutic goals with PWA and their families in order to take their input into account. The views of SLTs in the current study suggest that the main aim behind involving PWA and their family members in discussions surrounding goals is to incorporate realistic goals rather than a formal process of sharing decision making.

The findings of this theme show that SLTs in the Saudi context of aphasia rehabilitation take into consideration different aspects when identifying goals for PWA in aphasia therapy. The absence of a standardised method in the literature on how therapeutic goals should be identified in aphasia or neurological rehabilitation suggests that the process is highly context-based and influenced by different factors.

7.3.4 Theme four: Participation in goal-setting

Some PWA and their families in the current study reported sharing their value-based goals (religious activity goals) or needs with SLTs. Most PWA and their family members trusted the SLTs to make decisions about their therapeutic goals for them. Participants reported that effective participation in discussions surrounding therapeutic goals is influenced by contextual factors including condition-related factors (severity and comorbidity), knowledge of stroke and aphasia, family presence in therapy sessions, and service-related factors (SLTs' good manners, the need for supporting the involvement of PWA and their families, and the insufficient aphasia services).

In this study, Some PWA and their families emphasised the importance of participating alongside SLTs in setting therapeutic goals as they attributed that to their insight into their own needs. Some PWA who reported sharing their input at a later stage of therapy and a family member expressed that they asked their SLTs to work on reciting the Quran. Choosing to work on goals related to religious practices in aphasia therapy suggests that religious practices are highly affected by stroke and aphasia, as well as reflecting the strong presence of Islamic faith in Saudi culture, as reported above in the discussions of themes one and two.

On the other hand, most PWA and family members reported trust in SLTs as health care professionals whether they viewed participation in goal-setting as important or not. A possible interpretation can be that PWA and their family members appreciate being involved and listened to, but prefer SLTs to assume the main role of decision makers in relation to therapeutic goals in aphasia therapy. Trusting medical professionals in decision making has been reported in medical literature (Auerbach, 2001), and has also been viewed as being a reason for limited participation in goal-setting in stroke and other neurological rehabilitation literature, as individuals handed over decisions with regard to therapeutic goals to healthcare professionals whom they viewed as being experts (Berg, Askim, Balandin, Armstrong, & Rise, 2017; Bradley, Bogardus, Jr., Tinetti, & Inouye, 1999; Brown et al., 2014; Levinson, Kao, Kuby, & Thisted, 2005; Lloyd et al., 2014; Rosewilliam, Roskell, & Pandyan, 2011).

Data suggest that contextual factors are present in the dynamics of PWA's and their family members' participation in discussions surrounding therapeutic goals with SLTs. These contextual factors include condition-related factors (severity and comorbidity), knowledge of stroke and aphasia, family presence in therapy sessions, and service-related factors (SLTs' good manners, the need for supporting the involvement of PWA and their families, and the insufficient aphasia services).

Some participants in this study reported that the limited participation of PWA is related to the characteristics of the condition and to the severity of aphasia, which mirrors findings reported in medical rehabilitation literature (Bradley et al., 1999; Holliday et al., 2007; Leach et al., 2010; Rohde, Townley-O'Neill, Trendall, Worrall, & Cornwell, 2012).

The limited effective participation in goal-setting discussions in the current study was also attributed to insufficient knowledge of stroke and aphasia. In Australia and the UK, neurological rehabilitation patients' insufficient knowledge of the condition, as well as the processes of goal-setting and rehabilitation, has been associated with their involvement in goal-setting (Conneeley, 2004a; Holliday, Ballinger, & Playford, 2007; Laver, Halbert, Stewart, & Crotty, 2010; Leach, Cornwell, Fleming, & Haines, 2010; Schoeb, Staffoni, Parry, & Pilnick, 2014). Some PWA and their families in this study reported that their non-participation was because of their trust in SLTs as experts who possess sufficient knowledge, and some SLTs reported that effective participation is influenced by PWA's and SLTs' insufficient knowledge of the condition. Trusting healthcare professionals as experts possessing sufficient knowledge, and insufficient knowledge of the medical condition can be interrelated factors. Thompson (2007) linked the two factors by reporting that a low level of knowledge of the medical condition increases patients' trust in healthcare professionals.

Some SLTs in the current study reported that the presence of family members who can set and discuss goals with SLTs and their continuous presence in therapy sessions are factors related to effective participation in goal-setting. Family members' role and involvement was appreciated by SLTs in this study, and has been recognised in stroke and aphasia literature (Bamm & Rosenbaum, 2008; Levack et al., 2009; Mant, Carter, Wade, & Winner, 2000; Visser-Meily et al., 2006). However, family members' participation can sometimes impose a negative influence when they have different expectations from SLTs, as reported in theme five. This result is in line with the study conducted by Levack et al. (2009), as the researchers reported that familial involvement facilitated goal-setting in some cases; however, they were disruptive in other situations when they held their own goal agenda.

In relation to factors related to aphasia services, SLTs' manner was reported by one participant in which it can be a factor hindering or facilitating effective communication in sharing goals. The participant reported that SLTs' good manners facilitate effective communication and encourage him to approach SLTs when he needs to discuss a matter. A positive communication with SLTs and building a therapeutic relationship has been reported in the literature in relation to the involvement in goal-setting. In two systematic reviews conducted by Rose, Rosewilliam, and Soundy (2017) and Plant, Tyson, Kirk, and Parsons (2016), barriers to individuals' involvement in goal-setting in neurological and stroke rehabilitation settings were investigated, and barriers related to organisation and healthcare systems included factors such as the lack of staff time and shift work patterns that might hinder building a therapeutic relationship.

Some family members in this study reported factors related to supporting the involvement in the process by sharing adequate details on goals and progress, and also by the provision of visual materials on goals. In the literature on neurological rehabilitation goal-setting, supporting the involvement of individuals in goal-setting was reported to be helpful. The provision of visual materials on goals were reported to be helpful, as they helped to clarify expectations, guide therapy and monitor progress, in addition to facilitating familial involvement (Brown et al., 2014; Leach et al., 2010; Levack et al., 2009; Van De Weyer, Ballinger, & Playford, 2010).

Some participants in the current study also reported factors related to insufficient aphasia rehabilitation services. The lack of services was not identified in any of the studies reviewed by Rose, Rosewilliam, and Soundy (2017) and Plant, Tyson, Kirk, and Parsons (2016) in their systematic reviews. Travelling to large cities in order to receive aphasia rehabilitation services (e.g. the capital city of Riyadh, which is situated centrally within Saudi Arabia and geographically distant for many people), limitations of appointments, and insufficient rehabilitation beds in Saudi Arabia can influence accessibility of further services and limit people’s participation in goal-setting and therapy. The insufficient aphasia rehabilitation services in Saudi Arabia reported by some participants in the current study could be accounted for the high demand for rehabilitation services, specifically speech and language services, and the low number of SLTs and facilities that provide high-quality services to stroke survivors. The Saudi Ministry of Health (2018) reported that the number of Saudi and non-Saudi male and female SLTs is 147, and that the number of cases who attended MOH rehabilitation centres and departments for speech and language therapy has reached 43,173. The highest number of cases was noted in Riyadh (32,816 cases), while the lowest was observed in Najran (42 cases). An absence of cases that received speech and language therapy was observed in eight cities:

Hafr Al-Batin, Bishah, Tabok, Ha’il, Northern Border, Al-Baha, Al-Qurayat, and Qunfudah. The number of SLTs in relation to the Saudi population (34,218,169) and the cases which received speech and language therapy is relatively low. The number of working SLTs, the absence of cases in eight cities, and the fact that the highest number of cases was found in Riyadh indicate a shortage of workforce and a concentration of high-quality services in large cities. Aphasia services in Saudi Arabia are not heavily researched. Khoja and Sheeshah (2018) conducted a survey study in order to explore speech and language services in Saudi Arabia. They confirmed that services are insufficient in Saudi Arabia because of the low number of SLTs and the concentration of services in Riyadh, the Mecca region, and the Western Province. The researchers suggested increasing public and political awareness as a means by which to raise the number of SLTs in Saudi Arabia, as well as providing home programmes and utilising telehealth methods to cover rural areas.

The trust that PWA and their family members have in SLTs as the main decision makers in this theme can be viewed from a cultural perspective as discussed below.

7.3.4.1 Trust in health care professionals from a cultural perspective

In the existing neurological rehabilitation literature, there is no evidence reported of the relationship between high trust in health care professional and the cultural context. Saudi Arabia is governed by a monarchy political system, where decisions, to a large extent, are made by the king and senior members in the royal family (Alsultan, 2013). A possible interpretation can be that PWA and their families who come from cultures where decisions are mainly made be senior members in political system or in society (collectivist cultures) view decision making as a responsibility of the expert assigned to be in charge. Hence, they might prefer important decisions to be made by SLTs in aphasia therapy.

In Islam, trusting others is highly promoted because God's trust is given to individuals; therefore, they become trustees for everything in their property, including job positions and tangible items (Lewis, 2001). Individuals who strongly adhere to this principle hold values of honesty, truthfulness and integrity because they are constantly evaluating their roles as trustees. SLTs in a Muslim context are considered trustees in providing therapy to PWA. Therefore, PWA's and families' trust in SLTs could be a subconscious reaction to trustees, or could be a response related to their insufficient knowledge of the condition or to positive values that SLTs exhibit.

The findings of this theme suggest that the dynamics of PWA's and their family members' participation in goal-setting in Saudi aphasia rehabilitation is highly context-based as it is influenced by contextual factors including the cultural aspect.

7.3.5 Theme five: Expectations in aphasia therapy

Participants reported both matched and unmatched expectations in aphasia therapy. Some SLTs stated that the effective participation of PWA and their families in goal-setting facilitates reaching matched expectations in aphasia therapy. As a result of matched expectations, increased motivation and cooperation of PWA and their families can be observed as reported by SLTs. On the other hand, unmatched expectations can negatively influence aphasia therapy by pressuring PWA, decreased motivation, and disrupting therapy.

A number of SLTs in the current study reported that effective participation of PWA and their families in goal-setting and discussions surrounding therapeutic is critical to reach matched expectations, thus facilitating motivation and cooperation in therapy. It remains unclear in the literature as to whether the level of participation and the approach to goal-setting are associated positively with a rehabilitation outcome (Levack et al., 2016; Levack et al., 2006). However, some studies have reported that increased engagement can be related to satisfaction, motivation, and goal achievement, all of which lead to better functional outcomes (Leach et al., 2010; Turner-Stokes, Rose, Ashford, & Singer, 2015).

High expectations or different expectations in respect of therapeutic goals and activities were expressed by participants. The presence of high and different expectations amongst individuals receiving therapy and their families during rehabilitation has been reported several times in stroke and neurological rehabilitation literature (e.g. Huby, Stewart, Tierney, & Rogers, 2004; Leach, Cornwell, Fleming, & Haines, 2010; Levack, Siegert, Dean, & McPherson, 2009; Lloyd, Roberts, & Freeman, 2014; Plant, Tyson, Kirk, & Parsons, 2016; Scobbie, McLean, Dixon, Duncan, & Wyke, 2013; Young, Manmathan, & Ward, 2008). The presence of high expectations in the current study in relation to reaching some goals that families shared in aphasia therapy imposed a negative consequence similar to what has been reported by Levack, Siegert, Dean, and McPherson (2009). High expectations from family members can impose psychological pressure upon PWA, disrupt the flow of therapy, and distract PWA because they find themselves caught between what their families want and what SLTs want.

In this study, and to facilitate reaching matched expectations in relation to aphasia therapeutic goals, an SLT in this study reported that a family's high-level goals were incorporated as a long-term goal, which is similar to what Levack, Siegert, Dean, and McPherson (2009) reported in their study, wherein the SLT reframed the family's goal as a long-term goal that encompasses achievable small objectives. SLTs also reported that they mainly increase PWA's and families' knowledge of the case, whereby indicating that insufficient knowledge of the case is behind the appearance of unmatched expectations. Providing education on the case in order to manage expectations is consistent with what has been reported many times by SLTs in neurological rehabilitation literature (Leach, Cornwell, Fleming, & Haines, 2010; McClain, 2005).

Expectations is a complex concept in aphasia therapy. Worrall, (2006) reported that the presence of mismatched goals does not mean simply that SLTs did align their goals with what PWA want in therapy. Goal-setting is much more complex and it needs a thorough investigation in real clinical practice as Worrall, (2006) suggested. The theoretical background underpinning the practice of goal-setting in rehabilitation has not been researched thoroughly, as the majority of theories on goal-setting are derived from psychological literature (Playford et al., 2009; Wade, 2009). In their systematic review, Scobbie, Wyke, and Dixon (2009) identified five theories as being relevant to goal-setting, and capable of informing its practice in a medical context. In Scobbie, Wyke, and Dixon's (2009) systematic review, and in relation to brain injury rehabilitation, goal-setting theory (Locke & Latham, 2002) has been tested in randomised controlled trials, with positive results having been reported (Gauggel & Fischer, 2001; Gauggel, Leinberger, & Richardt, 2001; Gauggel & Billino, 2002; Gauggel, Hoop, & Werner, 2002). Gauggel and colleagues reported in their studies that setting specific and high goals resulted in a better performance when compared to 'do your best' goals. However, it has been argued that the testing of goal-setting efficacy in these studies was carried out in a less complex environment when compared to real-life clinical practice (Scobbie, Wyke, & Dixon, 2009). The goal-setting theory was developed in the field of industrial organisation psychology, and according to it, the specificity and difficulty of goals are key factors directing individuals' performance (Locke & Latham, 2002). In their theory, Locke and Latham (2002) argued that specific and difficult goals could increase an individual's effort in comparison to less challenging goals. However, Locke and Latham's (2002) theory might not be applicable to complex, real-life clinical practices, and also might conflict with the beliefs held in rehabilitation (Playford, Siegert, Levack, & Freeman, 2009). Locke and Latham (2002) view ambitious goals as being a mechanism for enhancing task performance, while in aphasia therapy, setting highly ambitious and unrealistic goals can decrease achievability. SLTs in the current study reported that they needed to manage the expectations of PWA and their families when they had unrealistic goals, as negative influences appeared in therapy, including low motivation, pressure on PWA, and disrupting the flow of therapy.

The findings of this theme suggest that goal-setting in real clinical practice is complex and requires further theoretical investigations. The findings also suggest that matched expectations influence aphasia therapy positively, and that the effective participation of PWA and their families in discussions surrounding therapeutic goals can facilitate reaching this outcome.

7.3.6 Theme six: The nature of goals in aphasia therapy

In terms of the types of goals set in therapy, all participant groups reported impairment-based, activity related, effective communication, and social participation goals. Some PWA and their families also reported general well-being and service- related goals.

It was challenging for PWA to express goals related to aphasia therapy, language or communication (other than “to speak” or “to express” for some individuals) without using Talking Mats^{TM}. Hence, a possible source of bias could be present because PWA selected communication-related goals from Talking Mats™ (e.g. to read, to write, to find a word you want to say). To reduce the level of bias, all goals in the scope of aphasia rehabilitation were reported, be they those expressed using Talking Mats™ or those expressed through interviews. A possible interpretation for PWA’s difficulty to express goals related to aphasia rehabilitation can be attributed to the fact that some language and communication aspects might be abstract concepts (e.g. grammatical errors in language processing or effective communication). Hence, thinking about or expressing such goals might be difficult for some individuals. Meanwhile, another possible interpretation can be that PWA prioritise returning to their state prior to the occurrence of stroke, when speaking in general was effortless and they were healthy, as some PWA reported general well-being goals. Wanting to return to a pre-stroke state has been reported in the finding of Worrall et al. (2011), as participants in their study expressed such information as a goal that they wanted in aphasia rehabilitation. Some family members in the current study expressed that they want their loved ones with aphasia to return to pre-stroke life. This suggests that for some family members, concerns are not focused on only one area, such as communication; rather, family members have different concerns, and the majority of them want their loved ones with aphasia to become healthy again and return to a pre-stroke status.

Most SLTs in this study reported setting impairment-based goals in aphasia therapy that specifically target language processing. Setting impairment-based goals is common amongst SLTs and has been reported in other studies (Laliberté, Alary Gauvreau, & Le Dorze, 2016; Leach et al., 2010; Rohde, Townley-O'Neill, Trendall, Worrall, & Cornwell, 2012). It has been proposed that impairment-based goals are commonly set by rehabilitation professionals, as it allows observing noticeable progress (Glazier, Schuman, Keltz, Vally, & Glazier, 2004; Salter, Camp, Pierce, & Mion, 1991).

For some PWA and their family members, working on religious activities was in aphasia therapy was important. This strong appreciation of goals that are aligned with PWA's Islamic religious faith in the current study is consistent with previous studies that highlighted the value of religion amongst individuals in Saudi neurological rehabilitation settings (Al-Haidary, Qannam, & Lam, 2015; Alqahtani, 2015). Religious activity goals were not reported by many SLTs. A possible interpretation can be that these goals are embedded within other impairment-based goals, or goals related to reading and writing.

In the current study, most goals for PWA that were reported by them and their families were related to effective communication as PWA and their families expressed that speaking and expressing is important for them. The findings are similar to what has been reported in the literature, as PWA in Australia and South Africa expressed goals a wide range of goals but with the majority being related to communication (Harty, Griesel, & van der Merwe, 2011; Pettit, 2014; Worrall et al., 2011). It can be that these studies, including the current one, are within the scope of aphasia rehabilitation; thus, the context of discussing goals with PWA in interviews is focused primarily on communication. Meanwhile, another possible reason could be related to the kinds of goals that fall under other categories (e.g. impairment-based goals), which might be vague and difficult for PWA to produce.

Some PWA and family members reported goals of social participation which mirrors studies reported in the literature as social participation has been appreciated by PWA since their goals were mostly linked to Activity and Participation domain of the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) framework (Harty, Griesel, & van der Merwe, 2011; Pettit, 2014; Worrall et al., 2011). Social participation goals in this study were limited, which is similar to what Laliberté et al. (2016) reported in their study, as SLTs perceived social participation to be the implicit aim behind the goals that they set.

In relation to service-related factors, information provision was reported by some PWA reflecting goals of PWA reported in the literature (Worrall et al., 2011). Some family members expressed intensive therapy and traveling abroad as goals for their loved ones with aphasia which can reflect their high expectations as discussed in theme five.

SLTs' therapeutic goals for PWA in this study reflect taking into account both impairment-based and functional goals for PWA in aphasia therapy, which mirrors the findings of Sherratt et al. (2011) and Leach et al. (2010). This reflects the emphasis on a more holistic approach to aphasia therapy, which was addressed by Hillis, Worrall, and Thompson (2008), and that no domain is more important than another (Galletta & Barrett, 2014). However, Sherratt et al. (2011) argued that the emphasis of PWA upon Activity and Participation goals in Worrall et al.'s (2011) study should guide SLTs in providing a more client-centred goal-setting that takes into consideration their individualised needs.

SLTs in this study documented and expressed goals for family members including providing education and teaching strategies, which is different from Sherratt et al.’s (2011) findings, as they reported that SLTs’ goals for family members were limited. Although data suggest that PWA can be supported in aphasia therapy, and that the impact of stroke and aphasia is targeted in therapy as therapeutic goals, little evidence indicates that families receive or have resources for support in the rehabilitation process. Concerns appeared in the data previously (theme two) according to which families’ lives are affected by stroke and aphasia and they might also need support. It has been reported in the literature that carers of stroke survivors and PWA need emotional and practical support (Le Dorze & Signori, 2010; Michallet et al., 2001, 2003). In the current study, families who attend therapy sessions might have received practical recommendations, since SLTs reported goals for family members including providing strategies and recommendations. However, it is possible that families do not receive enough emotional support. Hallé, Le Dorze, and Mingant (2014) in their study reported that significant others of PWA were referred to support services when needed. In the current study, however, no evidence of such services was mentioned by participants. A possible interpretation can be related to the focus on supporting clients in aphasia therapy in the Saudi context. Another possible interpretation can be that family members receive internal support from each other since the Saudi culture is more collectivist in comparison to other cultures.

The value of oral expression and rejection of alternative methods of communication expressed by some participants in the current theme can be viewed from a cultural perspective as discussed below.

7.3.6.1 The value of oral expression from a cultural perspective

Most family members reported that they want their loved ones with aphasia to express by speaking, and some expressed their rejection towards using alternative methods of communication. This might reflect a cultural attitude towards expressions through the use of alternative methods of communication. It can be that in Saudi culture, oral expression ability is an aspect to be judged upon. A possible interpretation can be related to the insufficient awareness of stroke and aphasia amongst society, as reported above in theme one. Hence, using alternative methods of communication might put PWA under the spotlight where others might interact with them with sympathy or insufficient knowledge. Meanwhile, another possible interpretation can be related to the value of oral expression and its link to how men are viewed in a more collectivist culture. In the three cases where family members expressed their rejection to alternative methods of communication in this study, PWA were males. As reported previously in theme one's discussion, views on masculinity is compromised after stroke in a collectivist culture where men are viewed as being responsible of the family. Using alternative methods of communication might influence men's role in families, or alter how the head of family is viewed by others. Therefore, some family members rejected using alternative methods of communication.

Findings of this theme suggest that all participant groups appreciate aphasia therapy goals that relate to different categories, and that SLTs aim at providing a balanced approach to therapy that is impairment-based and functional, albeit with limited goals related to social participation. family members expressed their rejection to use alternative methods of communication, which reflects views on using such methods in a collectivist culture. In aphasia therapy, SLTs set goals for family members which all relate to supporting PWA. SLTs aim at involving family members, but the actual involvement can be compromised by their non-presence in therapy sessions, or by their high expectations in therapy (as reported in theme four and five). The data suggest that goals for supporting family members are limited although they are also affected by stroke and aphasia.

7.4 Interrelating the findings of themes: A conceptualisation of goal-setting in Saudi aphasia rehabilitation

In the Saudi context of the current study, PWA and their families live in a collectivist culture where large or extended families are present, men are primarily the heads of families, and decisions are made by senior individuals in the hierarchy. In addition to collectivism, PWA and their family members live in a culture where Islamic faith is rooted in which daily activities and attitude are influenced by. The findings suggest that stroke and aphasia caused sudden life changes that heavily impacted PWA's and their families' lives. PWA and their families underwent the experience of stroke and aphasia with Islamic faith, that facilitates coping, albeit with insufficient knowledge of stroke and aphasia as some have reported. In addition, different aspects of PWA's and their families' lives become heavily affected by stroke and aphasia, one of which is the challenge encountered in practising religious activities, as they reported. The data suggest that vulnerability imposed after stroke influences how men are perceived in the Saudi culture. Views on masculinity are compromised by affected physical abilities and communication skills.

PWA, accompanied by family members, attended aphasia therapy with an emotional burden, changes in lifestyle, own attitude towards stroke and aphasia, and also with insufficient knowledge of the condition, which is also suggested to be present among society. SLTs take the role of decision makers in the process of goal-setting by identifying goals based on the individuality of the case and achievability of steps, in addition to involving PWA and their families in discussions surrounding therapeutic goals. Involving PWA and their families in discussions aims more at incorporating realistic goals and reaching matched expectations rather than a formal process of shared decision making. Some PWA and their families shared personal goals including value-based goals (religious activities) with SLTs, while most participants reported trusting SLTs in setting their therapeutic goals reflecting their preference for decisions to be made by the health care provider in charge of the case. The dynamics of involving PWA and their family members (by SLTs) in discussions surrounding therapeutic goals, and their participation in goal-setting is complex and highly influenced by contextual factors. Increased effective participation can facilitate reaching matched expectations in aphasia therapy as reported by SLTs. Matched expectations can lead to increasing motivations and cooperation, whereas unmatched expectation poses negative influence on aphasia therapy including disrupting the therapeutic process, pressuring PWA, in addition to a lack of motivation and cooperation with respect to improving as expressed by SLTs appears in aphasia therapy. In relation to therapeutic goals, PWA and their family members stressed on the religious activity goals and oral expression which reflects the value of Islamic faith and views on using alternative methods of communication in the Saudi culture. Figure 7.1 presents a conceptualisation of goal-setting in Saudi aphasia rehabilitation based on participants' data.

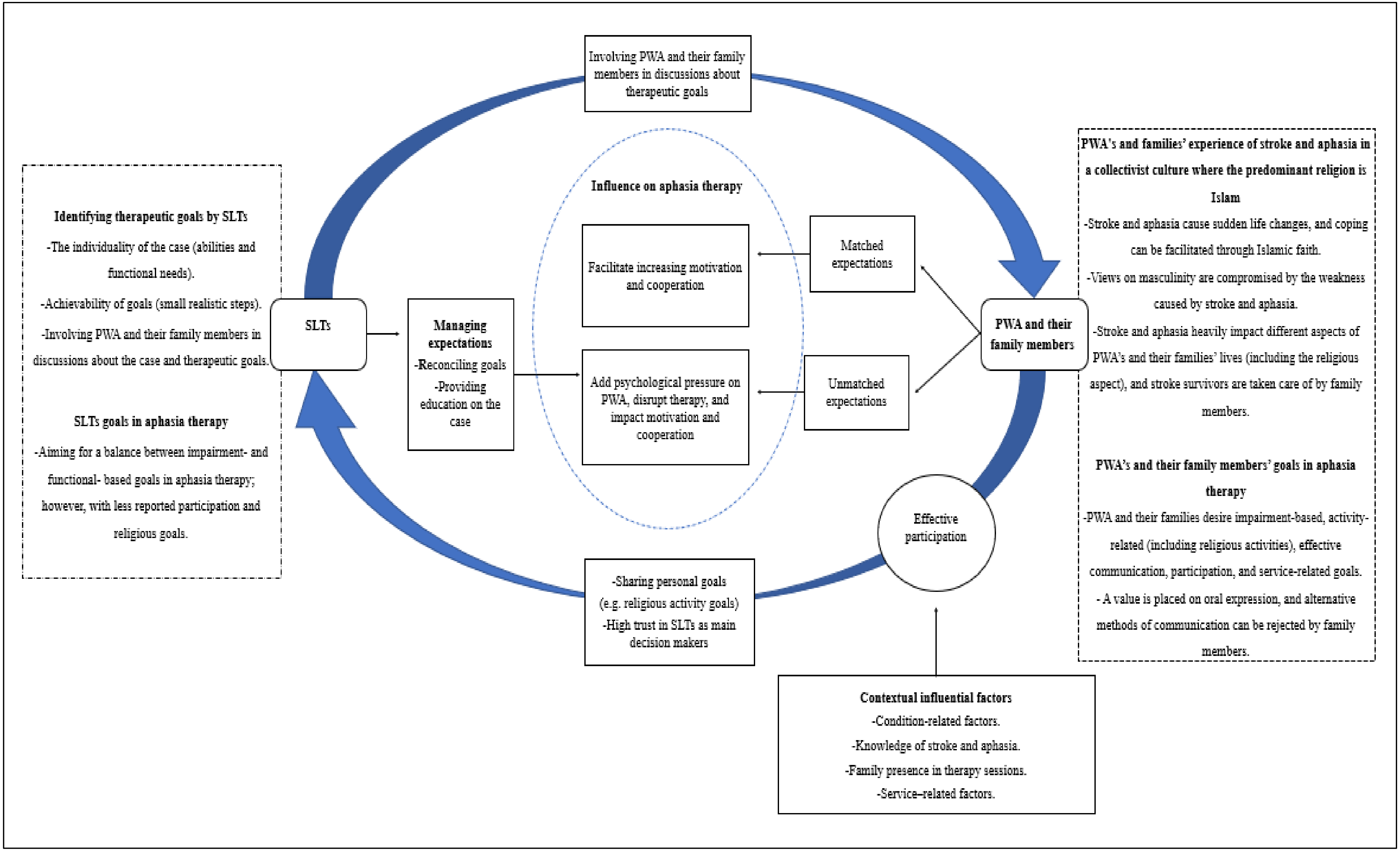


Figure 7.1 A conceptualisation of goal-setting in Saudi aphasia rehabilitation

The findings of this study suggest that goal-setting in Saudi aphasia rehabilitation is highly context-based, and that cultural factors have an influence on the complex dynamics of that process (e.g. Islamic faith and collectivism). The findings are in line with what Bradley et al. (1999), Hersh et al. (2012a), and Thompson (2007) suggested as they reported that therapeutic goals, goal-setting process in the medical context, and involvement in clinical decision-making are complex and context-based processes. The current study shed the light on a novel element which is the cultural influence that can be part of the complex process of goal-setting.

The findings of this study mirror what Bradley et al. (1999) suggested in their theory of goal-setting in medicine. Firstly, Bradley et al. (1999) suggested that goals can be generated from the embedded values of an individual. In this study, PWA who shared their goals with SLTs reported their desire to work on religious practice activities, which reflects the strong religious values that they hold. Secondly, Bradley et al. (1999) suggested that goals are hierarchical with a complex relationship between general and small goals. This is also reflected in the current study, as some SLTs reported setting small and achievable steps in order to reach the final goals. Thirdly, Bradley et al. (1999) suggested that the process of goal-setting is governed by modifying factors including interaction characteristics, disease characteristics and individual characteristics. Similarly, in this study, the participation of PWA and their families was influenced by contextual factors including condition-related factors, kknowledge of stroke and aphasia, family presence in therapy sessions, and service–related factors. However, the current study presents a novel aspect (the cultural context of the stroke and aphasia experience) which is suggested to have its influence on goal-setting.

The findings of this study also suggest that goal-setting in Saudi aphasia rehabilitation is informal and that the complexity of its dynamics directs the process to be therapist-led. Based on data reported by participants, goal-setting in the Saudi context of aphasia therapy is suggested to be classified as informal because the procedure does not follow a standardised guideline, such as the Goal Attainment Scale (Kiresuk & Sherman, 2016), and the process is not replicable in clinical practice (Prescott et al., 2015). Goal-setting is suggested to be classified as therapist-led, according to the main components reported by Leach, Cornwell, Fleming, and Haines (2010) as criteria for distinguishing three approaches to goal-setting in stroke subacute rehabilitation settings (therapist-controlled, therapist-led, and patient-focused). The components reported by Leach, Cornwell, Fleming, and Haines (2010) include the degree of patients' and their families' involvement in goal-setting in subacute rehabilitation, the foundations upon which goals are set (e.g. formal assessments), initial discussion surrounding the meaning of goal-setting, and patient and family education. Leach, Cornwell, Fleming, and Haines (2010) clarified that in therapist-controlled goal-setting, there is minimal patient and family input, while in therapist-led and patient-focused goal-setting, varying degrees of involvement can be seen. In the current study, SLTs reported identifying goals and undertaking discussions surrounding goals with PWA and their families; some PWA reported sharing their goals, while the majority reported non-participation. Since SLTs in the current study identify therapeutic goals, involve PWA and their families in discussions surrounding goals, in addition to providing education and constantly managing the expectations of PWA and their families, goal-setting is suggested to be therapist-led in the Saudi context of aphasia rehabilitation. A therapist-led goal-setting approach has been reported previously in stroke rehabilitation literature (e.g. Plant & Tyson, 2018; Rose, Rosewilliam, & Soundy, 2017).

Holliday, Antoun, and Playford (2005) reported that informal goal-setting is the most commonly used approach in clinical practice; however, this approach has not been researched in any depth in the literature (Prescott et al., 2015). In two systematic reviews that investigated decision making and approaches to goal-setting in neurological rehabilitation, the results differed in relation to the number of studies that adopted a collaborative approach to goal-setting. Prescott, Fleming, and Doig (2015) reported on 86 studies, finding that formal goal-setting approaches were adopted in 73 studies, while informal approaches were utilised in 22. Prescott, Fleming, and Doig (2015) stated that studies which reported adopting informal approaches were mostly client-centred/collaborative (15 studies), and that therapist-driven studies constituted seven studies. In another systematic review by Rose, Rosewilliam, and Soundy (2017), the researchers included 15 studies and stated that only two were client-centred, wherein decision making was a collaborative process, while the remainder were therapist-led with limited shared decision making. The number of studies that reported collaborative decision making in Prescott, Fleming, and Doig (2015) is higher than that in Rose, Rosewilliam, and Soundy (2017). This discrepancy could be attributed to the inclusion criteria used in both reviews or to the fact that informal goal-setting approaches have not been investigated in depth, as contended by Prescott, Fleming, and Doig (2015). Alternatively, the discrepancy could be an indicator of inconsistencies present in the literature with regard to the terminology used to describe goal-setting in clinical practice. To elaborate, Leach, Cornwell, Fleming, and Haines (2010) used three terms to describe three approaches with different levels of involvement, namely “therapist-controlled”, “therapist-led” and “patient-focused”, whereas Rose, Rosewilliam, and Soundy (2017) and Prescott, Fleming, and Doig (2015) used two terms, i.e. “therapist-led or patient-centred” and “therapist-driven or client-centred/collaborative”. In addition, Prescott, Fleming, and Doig (2015) referred to an approach involving collaboration which takes into consideration patients’ goals, namely “client-centred/collaborative”, while Rose, Rosewilliam, and Soundy (2017) referred to an approach involving shared decision making as being “patient-centred”. These inconsistencies in reporting and using terminology related to goal-setting might be related to the fact that goal-setting is a complex and multifactorial process that encompasses varying degrees of involvement by participants. Thus, there is a need for consistency and transparency in reporting, with authors adopting clearer terminology, thoroughly explaining meanings, and justifying using terminology related to goal-setting.

In summary, goal-setting in the current study is suggested to be highly context-based, informal, and therapist-led. Comparing the findings of this study to other settings in Saudi Arabia or to other Arab contexts is difficult because to the researcher's knowledge no similar studies have been reported in the literature. The majority of studies that investigated goal-setting in neurological rehabilitation were found to be conducted in the UK, Australia, and New Zealand.

7.5 Advocating a context-sensitive approach to goal-setting

As discussed in the previous section, goal-setting in Saudi aphasia rehabilitation is suggested to be highly context-based, and that the cultural influence appeared to contribute to that process. Exploring the cultural context of the experience of stroke and aphasia provided a new perspective into goal-setting in aphasia rehabilitation. Understanding PWA's and their families' attitudes towards stroke and aphasia, their challenges, and societal attitudes towards the condition adds knowledge to the state in which PWA and their families start aphasia therapy, as well as justifying some factors present in the complex dynamic of goal-setting (e.g. valuing religious activity goals and oral expression, trusting SLTs as health care professional).

Armstrong, Hersh, Hayward, Fraser, and Brown (2012) argued that understanding the experiences of individuals whose story are rarely revealed is valuable to inform research and clinical practice in order to provide culturally sensitive services. Moreover, the published UK, Australian, Canadian, and New Zealand guidelines for stroke management and rehabilitation advocate cultural sensitivity when providing services to stroke survivors (Hebert et al., 2016; Rudd et al., 2017; Stroke Foundation, 2010, 2017). The importance of understanding the influence of culture upon illness, rehabilitation, and recovery has been reported in these guidelines (Stroke Foundation, 2010). Yamey and Greenwood (2004) support that statement as they reported that rehabilitation teams need to have background knowledge of the religious coping strategies of individuals in order to support them when appropriate. In addition to coping with the condition, rehabilitation plans should be sensitive to the culture of stroke survivors (Hebert et al., 2016; Stroke Foundation, 2017), and rehabilitation goals should be relevant and meaningful to individuals who have suffered from stroke (Rudd et al., 2017). It has been reported also in the guidelines that understanding the cultural background of stroke survivors is necessary as it may influence their involvement in goal-setting (Stroke Foundation, 2017), and that participation in goal-setting is encouraged but that patients' preferences should be considered first (Rudd et al., 2017).

A level of cultural competency is therefore needed in order for the clinician providing the service to understand the interaction between a culture, the medical condition, and rehabilitation services (Alqahtani, 2015). The current study supports the claim that SLTs need a high level of cultural competency. Understanding the nature of the presence of contextual factors which influence attitudes towards rehabilitation amongst Saudi people, including PWA and their families, would help SLTs to provide support in more sensitive and nuanced ways. Research such as that reported in this thesis can ultimately help clinicians and researchers to increase their awareness of the cultural factors underlying the attitudes of patients and their families and lead to a more context-sensitive approach to rehabilitation and to goal-setting in particular, e.g. being aware of the strong presence of the Islamic faith in Saudi culture, which could shape PWA's and their families' attitudes towards stroke and aphasia, as well as placing value on religious practice activity goals in aphasia therapy. Moreover, such research can help SLTs understand the assumption that PWA and their families live in a culture where value is placed on oral expression and where masculinity is compromised by vulnerability after stroke or using alternative methods of communication. Also, such research can help SLTs understand the assumption that PWA and aphasia and their families might undergo the experience of stroke and aphasia with limited awareness about stroke and aphasia within society. In addition to that, this kind of research helps SLTs to understand how PWA and their families in a certain culture might view them as it is suggested in this study that SLTs are viewed as experts who possess sufficient knowledge and the main decision makers in aphasia therapy. Therefore, SLTs can be more sensitive to related arising issues in aphasia therapy.

The findings of the current study support the statements of Armstrong, Hersh, Hayward, Fraser, and Brown, (2012), encourage SLTs to adhere to stroke and aphasia guidelines, and also encourage researchers to investigate a variety of cultural context in relation to aphasia rehabilitation. The cultural context of the experience appears to be an essential aspect determining the approach of individuals to goal-setting. Understanding the cultural context of individuals' experience within which therapeutic goals are set should be considered carefully in research and clinical practice. By doing so, more context-sensitive recommendations and practices can be available to support PWA from different backgrounds. Therefore, the current study emphasises the role of SLTs in supporting PWA and their family members in aphasia rehabilitation and empowering them in the goal-setting process in a context-sensitive way. Based on participants' data, effective involvement of PWA and their family members in the process can facilitate reaching matched expectations between triad members (PWA, their family members, and SLTs); hence, increasing motivation, cooperation, and commitment to aphasia therapy.

Research that explores rehabilitation aspects from a cultural perspective is valuable to providing context-sensitive services to PWA. The following section provides clinical implications as well as implications for future research.

7.6 Implications for clinical practice and future research

7.6.1 Implications for clinical practice

This study emphasises the role of SLTs and rehabilitation specialists in goal-setting in aphasia rehabilitation. The study discussed the need for a context-sensitive approach to goal-setting that detects aspects within the cultural context and addresses them when setting therapeutic goals. Addressing these aspects in goal-setting allows SLTs to provide the appropriate support to PWA and their families and acknowledge their religious and cultural values. SLTs who derive from the same cultural background as that of PWA could be aware of some of these factors.

Stroke and aphasia can heavily change the lives of PWA and their families. The impact of stroke and aphasia can different aspects including psychological wellbeing, abilities and activities, social participation, and family dynamic. In clinical practice, SLTs should be aware of this impact and the risk of social isolation and the emotional burden. Since Islamic faith facilitate coping for some PWA and families, this aspect can be brought up in rehabilitation and utilised to decrease emotional burden.

Since there is insufficient awareness on stroke and aphasia among society individuals, and that some PWA and family members were not provided with sufficient information about their case, they can benefit from information provision that is related to the condition, coping, and also related to support services. The literature previously discussed stresses the need for and necessity of information provision for PWA and their families. Education on the condition, prognosis, rehabilitation process, and goal-setting should be considered during the whole period of rehabilitation. Some PWA and their families in the current study were confused at the stroke onset stage because of the limited information provided to them. Moreover, mismatched expectations occur frequently at the initial stages of therapy because of insufficient information on the case. Therefore, a strong emphasis on information provision at the onset of stroke and at the initial stages of speech and language therapy should be taken into consideration by SLTs. There is a need to call for more collaboration between stroke physicians and SLTs regarding the information provision procedures and supporting stroke survivors and families in accessing rehabilitation services.

The current study suggests that SLTs need to manage expectations and motivation in aphasia therapy in order to increase commitment to and satisfaction with therapy. One way in which to increase the chances of matched expectations and motivation is to get PWA and their families more engaged in goal-setting in order to empower them and so that they can develop a sense of ownership. To be culturally sensitive, and in therapeutic contexts in which PWA and their families trust SLTs and rely on them to make decisions, engagement in goal-setting could be increased by using visual tools such as workbooks or sheets to identify goals (Scobbie, McLean, Dixon, Duncan, & Wyke, 2013; Van De Weyer et al., 2010). Talking Mats^{TM} can be used to increase the involvement of PWA in goal-setting. Tools could be provided to PWA and their families to follow their progress in relation to relevant goals, in addition to the provision of regular feedback from SLTs. Another way in which to enhance interaction in goal-setting is to provide SLTs with interaction training for agenda setting (Rodriguez et al., 2008).

PWA need support from their families, while families themselves have reported that their lives have also been impacted by the condition. SLTs can address supporting both families and PWA by establishing support groups for each group within rehabilitation facilities. In addition, SLTs can conduct training programmes that target increasing awareness and communication participation. In clinical contexts such as Saudi Arabia, wherein high-quality aphasia services are available mainly in big cities, information provision and family training programmes should always be considered and practised so as to ensure that families are supported, strategies are practised in home environments, and services are available to people residing in rural or small cities. Different partner training programmes were reported in aphasia literature. These include Supporting Partners of People with Aphasia in Relationships and Conversation (SPPARC) (Lock et al., 2001), Supported Conversation for Adults with Aphasia (SCA) (Kagan, 1998), and conversation coaching (Holland, 1991). It has been reported in the literature that training programmes are effective and help in improving partners' skills with which to facilitate the communication of PWA; however, studies that investigate outcomes and associated factors in depth are still needed (Purdy & Hindenlang, 2005; Nina Simmons-Mackie, Raymer, & Cherney, 2016; Turner & Whitworth, 2006).

7.6.2 Implications for future research

The current study presents goal-setting in aphasia rehabilitation within the Saudi cultural context of experiencing stroke and aphasia. This study advocates a context-sensitive approach to goal-setting in order to support PWA and their families and acknowledge their religious and cultural values. Since the current study is the first to highlight the experience of stroke and aphasia in the Saudi context and explore goal-setting in the same context, further research can start here to investigate other aspects in depth.

Future qualitative research can focus on narrow aspects of PWA and their families experience of stroke and aphasia. For example, research can focus on the adaptation process of PWA and/or their families, interaction and family dynamics, and also the positive aspect of the experience and living successfully with aphasia. The current study suggests that families are a great source of support and that taking care of family members is rooted in Saudi culture. Further research could involve investigating the impact of implementing partner training programmes in Arab or Saudi culture.

Identified cultural aspects including religion and collectivism can be further researched. For example, research on a larger scale can explore and compare different religious beliefs in aphasia rehabilitation and their influence on goal-setting. Moreover, trust in SLTs as main decision makers in the process of goal-setting in aphasia rehabilitation can be explored and compared in different cultures.

Effective participation of PWA and their family members has been suggested by SLTs in the current study to be linked to expectations and motivation. Therefore, further research is required in order to explore in depth the effect of increasing involvement in goal-setting upon therapy and outcomes in the Saudi context. Research that investigates context-appropriate means and tools with which to engage PWA and their families in goal-setting and self-monitoring activities is needed. Since goal-setting is suggested to be informal in the current study, further research that explores the impact of formal goal-setting that adopts standardised procedures and tools such as the Goal Attainment Scale (GAS) (Kiresuk & Sherman, 2016) can be conducted in order to understand its implications. In settings in which rehabilitation teams meet regularly to discuss stroke patient rehabilitation goals, research could be conducted so as to explore their interaction in depth and investigate how goals are discussed, documented and monitored between team members.

The identified contextual factors that influence PWA's and their family members' effective participation in discussions surrounding goals can be studied further. In the current study, condition-related factors (severity and comorbidity), knowledge of stroke and aphasia, family presence in therapy sessions, and service-related factors (SLTs' good manners, the need for supporting the involvement of PWA and their families, and the insufficient aphasia services) were identified as contextual influential factors related to goal-setting in aphasia rehabilitation. For example, aphasia rehabilitation pathways can be investigated in different facilities so as to present recommendations and aim for standardised high-quality services.

In addition, further research can involve investigating information provision in aphasia rehabilitation and information that is accessible to PWA is also required for the Arab population, since all recommendations and guidelines in the literature are developed for English-speaking PWA.

In summary, significant emphasis on the role of SLTs has been highlighted in clinical implications. Education and information provision, managing expectations and increasing the sense of ownership, and supporting families are emphasised in clinical practice. For future research, the current study could be the starting point for future directions that further investigate the experience of stroke and aphasia and/or goal-setting in Saudi Arabia or other Arab countries or, alternatively, to compare the outcome of these factors in Arab and Western cultures.

The increased engagement that was suggested in the implications was based on SLTs' perspectives as they reported in the current study that effective participation can increase the chances of matched expectations. However, there is still a need to study the increased involvement systematically, using, for example, GAS or the Talking Mats, on a population that holds high trust in health care professionals as found in the Saudi context. Such need stems from acknowledging the presence of cultural variation, whereas the mainstream research on goal-setting has focused mainly on Western/English speaking countries. Emphasising a universal approach to goal-setting, or following procedures and recommendations that were reported in Western/English speaking countries, might not be always appropriate to individuals coming from different cultural backgrounds. That is why this current study supports conducting more research in different cultural contexts, and also supports a context-based approach that acknowledges variation among cultures. Such an approach should be tailored to a specific culture and highlights its unique aspects. Having considered the practical and future implications, the following section highlights the strengths and limitations of this study.

7.7 Contribution of the study

From a theoretical perspective, the current study contributes to the growing body of aphasia-related qualitative research. The investigation in the current study was conducted from three viewpoints for a deep conceptualisation that encompasses multiple perspectives. Therefore, a foundation of current goal-setting practice in aphasia rehabilitation within the cultural context of the experience of stroke and aphasia has been established for further future research.

As previously mentioned, research into the experience of stroke and aphasia forms a large body of research in which the majority of studies were conducted in Western countries or with English-speaking individuals (e.g. Greenwood & Mackenzie, 2010; Hesamzadeh, Dalvandi, Bagher Maddah, Fallahi Khoshknab, & Ahmadi, 2015; Luker et al., 2017; Nasr et al., 2016; Simeone et al., 2015). In a similar context, the literature shows that goal-setting studies in stroke and aphasia rehabilitation were conducted (e.g. Berg et al., 2017; Brown et al., 2014; Hersh, Sherratt, et al., 2012; Howe et al., 2012; Levack et al., 2009; Levack, Dean, Siegert, &

Mcpherson, 2011; Parsons, Plant, Slark, & Tyson, 2016; Rohde, Townley-O’Neill, Trendall, Worrall, & Cornwell, 2012b; Rosewilliam, Sintler, Pandyan, Skelton, & Roskell, 2016; Sherratt et al., 2011; Worrall et al., 2011). Since the experience of stroke and aphasia and of therapeutic goal-setting for aphasia has not been investigated previously in Saudi Arabia, this study addresses two major areas in research within a specific cultural context that differs from what has been reported in the literature.

From a clinical perspective, this study places an emphasis on understanding the cultural context of PWA and their family members, and advocates a context-sensitive service provision in aphasia rehabilitation. This study provides a new perspective, as there is no study in the literature that explored goal-setting from a wider cultural perspective. Understanding goal-setting in aphasia rehabilitation within the cultural context of experiencing stroke and aphasia provided an insight into broader aspects rooted in the culture that can be present in aphasia rehabilitation (e.g. religious faith, views on vulnerability after stroke in a collectivist culture). Such research contributes to enhancing context transparency and transferability of findings, optimising cultural competency in aphasia rehabilitation, and providing context sensitive services to PWA and their families in rehabilitation.

7.8 Research rigour, strengths and limitations

In the process of conducting the research project in order to achieve the aim of the study, research rigour was constantly considered and evaluated. As a researcher, being critically reflective on certain steps or bias that could be present in the study is important in monitoring and enhancing the quality of the study (Cypress, 2017). Such reflexivity is demonstrated by critically reporting the strengths and limitations in the current section. The strengths of the current study can be discussed within the framework of key steps in the research design which include the literature review, data collection, data analysis, and data presentation.

The literature review in this study was conducted in an in-depth manner in order to build a contextual and methodological foundation for the study. In the literature review, which is presented in chapter 1 (Literature review), a contextual background to the study was presented in order to allow for the transferability of findings to another context. In qualitative research, it is the researcher's responsibility to provide a rich presentation and description of the study context so as to give the reader the opportunity to transfer and apply findings to other or similar contexts (Noble & Smith, 2015; Shenton, 2004). Moreover, a systematic review was conducted before data collection and reported in detail in chapter 2 (Development of research materials). The systematic review aimed to synthesise interview topics and questions directed to PWA, their families, and SLTs, and reported in the literature on the experience of stroke and aphasia and goal-setting and neurological rehabilitation. It resulted in developing interview schedules that covered all themes reported in the literature. This suggests that participants in the current study were interviewed and asked questions that covered major aspects related to investigated topics and reported in literature. Therefore, the findings of this study are suggested to be relatively comprehensive. Furthermore, methodological decisions and justifications were highly supported by the literature. Chapter 3 (Selection of analysis and translation methods) presents the translation and analysis methods chosen in the current study with transparent justifications and details. Such transparency in respect of reporting translation and analysis methods aimed to increase the objectivity of the research. In addition, presenting other analysis methods reported in aphasia literature as well as justifications for the chosen ones demonstrates the researcher's critical skills and judgment on the research methods available. As part of the in-depth literature review, a set of predetermined recommendations reported in the literature were followed in the current study so as to enhance the trustworthiness of the findings. The steps that were taken in the current study aimed to enhance the credibility, dependability, transferability and confirmability. These steps are reported in chapter 3 under *3.4.1.6 Strategies to ensure trustworthiness of findings.*

With regard to data collection, a strength of this study is demonstrated in the standardised interviewing procedure and in facilitating the communication of PWA to increase their involvement. The interview schedules, which were developed based on the systematic review, allowed the researcher to conduct interviews in a standardised manner. Details of the interviewing procedures are provided thoroughly in chapter 4 under *4.4.3 Interviewing participants.* This standardisation of procedures amongst participants enhanced the consistency of steps and aimed to minimise potential bias. With regard to facilitating the communication of PWA, the current study adopted different methods reported in the literature in order to increase PWA's involvement in the study. PWA's expression and comprehension were supported by methods in different stages of this project. An aphasia-friendly ethics form and information sheets were developed according to the literature and provided to PWA. Moreover, aphasia-friendly interviewing materials and supporting conversation strategies were used during interviews. Aphasia-friendly materials for PWA in this study are reported in detail in chapter 2 under *2.4 Developing aphasia-friendly materials.* The adoption of communication facilitation methods in this study aimed to enhance the credibility of PWA's responses, therefore enhancing the trustworthiness of the research findings.

A strength of the analysis methods in this study lies in data triangulation, reliability checks, and using grounded theory techniques. In this study, two forms of data triangulation are demonstrated. Interview data was collected from three groups of participants (constituting

PWA, their families, and SLTs) and analysed using Flick's (2014) approach. This form of triangulation provides an in-depth understanding of a phenomenon under study, reduces potential researcher bias and also ensures the credibility and truth of findings. Another form of data triangulation is seen in this study. Data on PWA’s therapeutic goals were collected from PWA’s clinical records and also from PWA and their SLTs; thus, credibility was also ensured. Since analysis was conducted by the main researcher, the reliability of results was taken into consideration. Reliability checks were completed with other colleagues in order to check codes and the translation of data. Furthermore, the use of grounded theory techniques was another strength in this study. The grounded theory technique of constant comparisons allowed for an iterative manner of data analysis that promoted the constant revision and refining of themes so as to build a comprehensive thematic structure. Using Strauss' (1987) paradigm to go beyond a descriptive account into interpreting situations present in data was also a strength of the data analysis. Strauss (1987) paradigm is reported in detail in chapter 3 under *3.4.2 Data interpretation*.

A strength of the data presentation lies in the fact that the results are presented with rich quotations and supported by diagrams. In chapter 6 (Results), the results are reported with rich responses of PWA, their families, and SLTs. This transparent presentation of quotations enhances the credibility of the findings and also the transferability to other contexts, as the reader is given the chance to judge the data. Results are also summarised in a Venn diagram in order to present commonalities in perspectives amongst the participant groups. The presentation of data in text and diagrams enhances the credibility of interpretation and also minimises potential bias. The discussion surrounding the findings, which was presented previously in this chapter, is also a strength of the study. The findings are discussed transparently within the context of the study and also in relation to other contexts in the literature reported. In fact, contextual transparency is advocated in the current study. Therefore, the transferability of findings is supported because the reader is enabled to compare and make a decision. For example, the Saudi context shares common aspects with other Arab contexts, such as the presence of collectivist cultures or the predominance of the Islamic religion. Thus, readers are supported in judging the applicability of linking the findings and implications to their own context.

Although certain areas of strength have been outlined above, the limitations of this study should be acknowledged. In the current study, the sample size was 29, which is small compared to some similar studies such as Hersh (2009), and Brown, Worrall, Davidson, and Howe (2011). Recruitment was challenging for a variety of reasons including the complexity of stroke and aphasia, and the pre-determined inclusion and exclusion criteria for PWA that restricted participation to individuals who could communicate their thoughts and needs. In addition, recruitment was challenging because of the nature of the research setting. Eligible participants, for example, in hospitals may have been discharged suddenly and become unable to participate in the study because they either travelled back to their home cities or lost interest in the study. Outpatients may also have refused to participate because they may have felt therapy time would be neglected which was a priority compared with participating in the study. In addition to those challenges, the triadic nature of recruitment posed some difficulties, for example, searching for triad members who would all agree to participate.

Although the sample size was small, it is considered acceptable in qualitative research, as evidenced in previous studies (discussed in *1.7.3.2 Subject recruitment and sampling).* It could be argued that because of the number of participants in a study, the transferability of findings is compromised. This issue was considered in the current study. Sampling was purposive to achieve maximum variation in participants (discussed in detail in *4.2.2 Sampling)*. When certain pre-determined factors vary amongst participants in a sample, the representativeness of the larger population is enhanced. In addition to adopting a purposive sampling method, a rich and transparent presentation of the Saudi context was highlighted (chapters 1 and 7) to enhance the transferability of the findings. Thus, the reader can judge and reflect on the findings in other contexts, for example, other Arab contexts or other cultures where societies are described as collectivist.

An additional limitation in this study was the short duration of interviews with some of the participants, which may have resulted in a lack of in-depth data being collected. The duration of certain interviews was short because those participants went to the hospital for a therapy session in addition to an interview, and, therefore, their time was limited. For other participants, the screening and interview procedures were conducted in the same session, thus, the interview time may have been reduced or the participants may have felt tired. The decision to conduct the screenings and interviews in the same session was made based on suggestions from the SLT to ensure that inpatients were interviewed before they were discharged from therapy and that outpatients were interviewed before their next session which can be far apart. Another justification for the short interview duration for some SLTs could be attributed to a busy schedule and limited availability between sessions. Moreover, sharing information was easier for some participants than others because of various factors including mood, personality, availability, and communication skills.

Although the interview duration for some participants was short, the researcher prompted all participants during interviews and used research-based materials to elicit responses from PWA with the aim of collecting in-depth data.

In the current project, interview questions were developed using literature from mostly Western and English-speaking countries. Using this method might have compromised addressing relevant topics in relation to the Saudi population. One way to resolve that issue was by conducting a focus group, for example with SLTs, in order to discuss the systematic review results and provide guidance for the interview questions. This method would have brought the perspectives of individuals from the same culture into the interview questions in order to elicit more relevant data during the interviews. However, due to time and resource constraints, this method was not applied in the current project.

Although interview questions were developed using literature from Western and English-speaking countries, the researcher reported the cultural context transparently, took into consideration emergent topics during interviews, and interpreted data based on the context that was drawn from participants' experience of stroke and aphasia, and discussed relevant issues with colleagues who came from similar and different cultures.

As reported in chapter 4, in *4.4.5 Audio and video recording,* only three participants agreed to be video recorded in the current study. Therefore, it should be acknowledged that some of the nuanced information might have been lost. In order to preserve the data, the researcher recorded subjective field notes during and after each participant’s interview. Those field notes were not used in the coding process. Field notes were used by the researcher to reflect on and to understand the case more deeply when writing memos and case descriptions.

Another limitation of this study is related to time and resource constraints. Due to the types of constraints, the majority of work in this study was conducted by the main researcher, in addition to the fact that participants’ responses were not validated by them. Thus, a level of researcher bias could have been imposed. To minimise this bias in the data, the researcher held regular meetings with supervisors, regular discussions with colleagues, and conducted reliability checks. In addition, the triangulation of data in relation to views and sources contributed to minimising bias and enhancing the credibility of the findings.

7.9 Conclusion

In conclusion, the three objectives of this study, which aimed to explore therapeutic goal-setting in aphasia rehabilitation within the cultural context of experiencing stroke and aphasia in Saudi Arabia, were achieved.

The first objective was to explore the views of participants on the experience of stroke and aphasia since this area is understudied in cultures other than Western or English-speaking countries. Details on the experience of stroke and aphasia and its context were presented from participants' views in chapter 6 and discussed in this chapter.

The second objective was to explore therapeutic goal-setting for aphasia from participants' views. An in-depth presentation of participants' views on goal-setting in aphasia therapy were presented in chapter 6 and discussed as well in this chapter.

The third objective was to conceptualise therapeutic goal-setting in aphasia rehabilitation based on participants' views and factors that were investigated against the background of Saudi cultural context and other contexts reported in the literature.

The Findings of the current study suggest that goal-setting in Saudi aphasia rehabilitation is highly context-based, and that cultural factors have an influence on the complex dynamics of that process (e.g. Islamic faith and collectivism). The findings of this study also suggest that goal-setting in Saudi aphasia rehabilitation is informal and that its complexity directs the process to be therapist-led. The findings emphasise the role of SLTs in empowering PWA and their family members by supporting their effective involvement in the process of goal-setting in a context sensitive way. Effective involvement is suggested to be a facilitator to reaching matched expectations which can increase motivation, cooperation, and commitment to aphasia therapy. Practical recommendations based on the findings of this study are presented under *7.6.1 Implications for clinical practice*. Furthermore, this study advocates contextual transparency in research and a context-sensitive approach to goal-setting in aphasia rehabilitation. Further research is needed in order to build knowledge in that area and also to investigate other topics surrounding goal-setting in the Saudi context.

References

Al-Amer, R., Ramjan, L., Glew, P., Darwish, M., & Salamonson, Y. (2016). Language translation challenges with Arabic speakers participating in qualitative research studies. *International Journal of Nursing Studies*, *54*, 150–157.

Al-Dabbagh, M., & Gargani, G. (2018). Saudi Arabia. *Arab Family Studies: Critical Reviews*, 275–294. https://doi.org/10.1093/oso/9780198840848.003.0011

Al-Eithan, M. H., Amin, M., & Robert, A. A. (2011). The effect of hemiplegia/hemiparesis, diabetes mellitus, and hypertension on hospital length of stay after stroke. *Neurosciences (Riyadh)*, *16*(3), 253–256.

Al-Haidary, Hisham, Qannam, H., & Lam, T. (2015). Development of a rehabilitation goal menu for inpatients with neurological disorders: application in a Saudi Arabian context. *Clinical Rehabilitation*, *29*(10), 1002–1012. https://doi.org/10.1177/0269215514561877

Al-jadaan, A. F. N. (2014). Assessing the Quality of Life among Saudi Patients with Aphasia after Stroke, 1–129.

Al-Jadid, M. S., & Robert, A. A. (2010). Determinants of length of stay in an inpatient stroke rehabilitation unit in Saudi Arabia. *Saudi Med J*, *31*(2), 189–192.

Al-Senani, F., Al-Johani, M., Salawati, M., ElSheikh, S., AlQahtani, M., Muthana, J., … Saver, J. L. (2019). A national economic and clinical model for ischemic stroke care development in Saudi Arabia: A call for change. *International Journal of Stroke*, *14*(8), 835–842. https://doi.org/10.1177/1747493019851284

Al Jadid, M. S. (2011). Rehabilitation medicine in the Kingdom of Saudi Arabia. *Saudi Med J*, *32*(9), 962–963.

Al Khathaami, A. M., Algahtani, H., Alwabel, A., Alosherey, N., Kojan, S., & Aljumah, M. (2011). The Status of Acute Stroke Care in Saudi Arabia: An Urgent Call for Action! *International Journal of Stroke*, *6*(1), 75–76.

Al Khathaami, A. M., Mohammad, Y. O., Alibrahim, F. S., & Jradi, H. A. (2018). Factors associated with late arrival of acute stroke patients to emergency department in Saudi Arabia. *SAGE Open Medicine*, *6*, 205031211877671.

https://doi.org/10.1177/2050312118776719

Alaqeel, A., AlAmmari, A., AlSyefi, N., Al-Hussain, F., & Mohammad, Y. (2017). Stroke Awareness in the Saudi Community Living in Riyadh: Prompt Public Health Measures Must Be Implemented. *Journal of Stroke and Cerebrovascular Diseases*, *23*(3), 500–504. https://doi.org/10.1016/j.jstrokecerebrovasdis.2013.04.011

Almoajel, A. M. (2012). Hospitalized patients' awareness of their rights in Saudi governmental hospital. *Middle-East Journal of Scientific Research*, *11*(3), 329–335.

Almutairi, K. M., & Moussa, M. (2014). Systematic review of quality of care in Saudi Arabia, *35*(8), 802–809.

Alqahtani, M. M. (2015). Evaluating patients'needs among rehabilitation setting. Human: Journal for Interdisciplinary Studies, 5(2).

Alqahtani, M. (2015). Understanding the Sociocultural Health Belief Model Influencing Health Behaviors among Saudi Stroke Survivors. *Neuroscience and Medicine*, *06*(04), 149–159. https://doi.org/10.4236/nm.2015.64023

Alrajeh, S., Awada, A., Niazi, G., & Larbi, E. (1993). STROKE IN A SAUDI-ARABIAN NATIONAL GUARD COMMUNITY - ANALYSIS OF 500 CONSECUTIVE CASES FROM A POPULATION-BASED HOSPITAL. *Stroke*, *24*(11), 1635–1639.

Anderson, S., Keating, N., & Wilson, D. (2017). Reconciling marriage and care after stroke. *Canadian Journal on Aging*, *36*(3), 386–401. https://doi.org/10.1017/S0714980817000241

Appelros, P., Stegmayr, B., & Terént, A. (2009). Sex differences in stroke epidemiology. *Stroke*, *40*(4), 1082–1090.

Armstrong, E., Hersh, D., Hayward, C., Fraser, J., & Brown, M. (2012). Living with aphasia: Three Indigenous Australian stories. *International Journal of Speech-Language Pathology, 2012, Vol.14(3), p.271-280*, *14*(3), 271–280. https://doi.org/10.3109/17549507.2011.663790

Ashton, C., Aziz, N. A., Barwood, C., French, R., Savina, E., & Worrall, L. (2008). Communicatively accessible public transport for people with aphasia: A pilot study.

Aphasiology, *22*(3), 305–320. https://doi.org/10.1080/02687030701382841

Auerbach, S. M. (2001). Do patients want control over their own health care? A review of measures, findings, and research issues. *Journal of Health Psychology*, *6*(2), 191–203. https://doi.org/10.1177/135910530100600208

Avent, J., Glista, S., Wallace, S., Jackson, J., Nishioka, J., & Yip, W. (2005). Family information needs about aphasia. *Aphasiology*, *19*(3–5), 365–375. https://doi.org/10.1080/02687030444000813

Bäckström, B., Asplund, K., & Sundin, K. (2010). The meaning of middle-aged female spouses' lived experience of the relationship with a partner who has suffered a stroke, during the first year postdischarge. *Nursing Inquiry*, *17*(3), 257–268. https://doi.org/10.1111/j.1440-1800.2010.00490.x

Banks, P., & Pearson, C. (2004). Parallel lives: Younger stroke survivors and their partners coping with crisis. *Sexual and Relationship Therapy*, *19*(4), 413–429. https://doi.org/10.1080/14681990412331298009

Barnard, R A, Cruice, M. N., & Playford, E. D. (2010). Strategies Used in the Pursuit of Achievability During Goal Setting in Rehabilitation. *Qualitative Health Research*, *20*(2), 239–250. https://doi.org/10.1177/1049732309358327

Barnard, Rachel A, Cruice, M. N., & Playford, E. D. (2010). Strategies Used in the Pursuit of Achievability During Goal Setting in Rehabilitation. *Qualitative Health Research*, *20*(2), 239–250. https://doi.org/http://dx.doi.org/10.1177/1049732309358327

Bastiaanse, R., & Jonkers, R. (1998). Verb retrieval in action naming and spontaneous speech in agrammatic and anomic aphasia. *Aphasiology*, *12*(11), 951–969.

Beckley, F., Best, W., & Beeke, S. (2017). Delivering Communication Strategy Training for People with Aphasia: What Is Current Clinical Practice? *International Journal of Language & Communication Disorders*, *52*(2), 197–213.

Bendz, M. (2003). The first year of rehabilitation after a stroke - From two perspectives. *Scandinavian Journal of Caring Sciences*, *17*(3), 215–222. https://doi.org/10.1046/j.1471-6712.2003.00217.x

Berelson, B. (1971). *Content analysis in communication research.* Glencoe, Ill.: Free P.

Berg, K., Askim, T., Balandin, S., Armstrong, E., & Rise, M. B. (2017). Experiences of participation in goal setting for people with stroke-induced aphasia in Norway. A qualitative study. *Disability and Rehabilitation*, *39*(11), 1122–1130. https://doi.org/10.1080/09638288.2016.1185167

Beringer, A., Tönsing, K., & Bornman, J. (2013). The self-determined and partner-predicted topic preferences of adults with aphasia. *Aphasiology*, *27*(2), 227–251. https://doi.org/10.1080/02687038.2012.744809

Bindawas, S. M., & Vennu, V. S. (2016). Stroke rehabilitation: A call to action in Saudi Arabia. *Neurosciences*, *21*(4), 297–305. https://doi.org/10.17712/nsj.2016.4.20160075

Birks, M., Chapman, Y., & Francis, K. (2008). Memoing in qualitative research: Probing data and processes. *Journal of Research in Nursing*, *13*(1), 68–75.

Boles, L. (2006). Success stories in aphasia. *Topics in Stroke Rehabilitation*, *13*(1), 37–43. https://doi.org/10.1310/29WX-32LE-A21H-3JQJ

Bornman, J., & Murphy, J. (2006). Using the ICF in goal setting: Clinical application using Talking Mats®. *Disability and Rehabilitation: Assistive Technology*, *1*(3), 145–154. https://doi.org/10.1080/17483100612331392745

Bowling, A. (2014). *Research methods in health : investigating health and health services* (Fourth edi).

Bradley, E. H., Bogardus, S. T., Tinetti, M. E., & Inouye, S. K. (1999). Goal-setting in clinical medicine. *SOCIAL SCIENCE & MEDICINE*, *49*(2), 267–278. https://doi.org/10.1016/S0277-9536(99)00107-0

Brady, M. C., Kelly, H., Godwin, J., Enderby, P., & Campbell, P. (2016). Speech and language therapy for aphasia following stroke. *Cochrane Database of Systematic Reviews*. https://doi.org/10.1002/14651858.CD000425.pub4

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Braunack-Mayer, A., & Hersh, D. (2001). An ethical voice in the silence of aphasia: judging understanding and consent in people with aphasia.

Breitenstein, C., Grewe, T., Flöel, A., Ziegler, W., Springer, L., Martus, P., … Baumgaertner, A. (2017). Intensive speech and language therapy in patients with chronic aphasia after stroke: a randomised, open-label, blinded-endpoint, controlled trial in a health-care setting. *The Lancet*.

Brennan, A., Worrall, L., & McKenna, K. (2005). The relationship between specific features of aphasia-friendly written material and comprehension of written material for people with aphasia: An exploratory study. *Aphasiology, 19*(8), 693–711. https://doi.org/10.1080/02687030444000958

Brown, K., Worrall, L., Davidson, B., & Howe, T. (2011a). Exploring speech-language pathologists' perspectives about living successfully with aphasia. *International Journal of Language & Communication Disorders, 46*(3), 300. https://doi.org/10.3109/13682822.2010.496762

Brown, K., Worrall, L., Davidson, B., & Howe, T. (2011b). Living successfully with aphasia: family members share their views. *Top Stroke Rehabil*. https://doi.org/10.1310/tsr1805-536

Brown, K., Worrall, L. E., Davidson, B., & Howe, T. (2012). Living successfully with aphasia: A qualitative meta-analysis of the perspectives of individuals with aphasia, family members, and speech-language pathologists. *International Journal of Speech-Language Pathology*, *14*(2), 141–155. https://doi.org/10.3109/17549507.2011.632026

Brown, M., Levack, W., McPherson, K. M., Dean, S. G., Reed, K., Weatherall, M., & Taylor, W. J. (2014). Survival, momentum, and things that make me "me": Patients' perceptions of goal setting after stroke. *Disability and Rehabilitation*, *36*(12), 1020–1026. https://doi.org/10.3109/09638288.2013.825653

Brunstein, J. C., Dangelmayer, G., & Schultheiss, O. C. (1996). Personal Goals and Social Support in Close Relationships: Effects on Relationship Mood and Marital Satisfaction. *Journal of Personality and Social Psychology*, *71*(5), 1006–1019.

Brunstein, J. C., Schultheiss, O. C., & Maier, G. W. (1999). Action & Self-

Development: Theory and Research Through the Life Span. Thousand Oaks: SAGE Publications, Inc. https://doi.org/10.4135/9781452204802

Camak, D. J. (2015). Addressing the burden of stroke caregivers: a literature review. *Journal of Clinical Nursing*, *24*(17–18), 2376–2382.

Campbell, J., Quincy, C., Osserman, J., & Pedersen, O. (2013). Coding In-depth Semistructured Interviews: Problems of Unitization and Intercoder Reliability and Agreement. *Sociological Methods and Research*, *42*(3). Retrieved from http://search.proquest.com/docview/1437628588/

Carlsson, E., Paterson, B. L., Scott-Findlay, S., Ehnfors, M., & Ehrenberg, A. (2007). Methodological issues in interviews involving people with communication impairments after acquired brain damage. *Qualitative Health Research.* [Thousand Oaks, Calif.] : https://doi.org/10.1177/1049732307306926

Carod-Artal, J., Egido, J. A., González, J. L., & Seijas, E. V. (2000). Quality of life among stroke survivors evaluated 1 year after stroke: Experience of a stroke unit. *Stroke*, *31*(12), 2995–3000. https://doi.org/10.1161/01.STR.31.12.2995

Critical Appraisal Skills Programme (CASP). (2017). Retrieved from https://casp-uk.net/casp-tools-checklists/

Ch’ng, A. M., French, D., & McLean, N. (2008). Coping with the challenges of recovery from stroke: Long term perspectives of stroke support group members. *Journal of Health Psychology*, *13*(8), 1136–1146. https://doi.org/10.1177/1359105308095967

Charmaz, K. (2006). *Constructing grounded theory : a practical guide through qualitative analysis*. London: SAGE.

Chen, H., & Boore, J. R. P. (2010). Translation and back-translation in qualitative nursing research: methodological review. *Journal of Clinical Nursing*, *19*(1-2), 234–239.

Chen, L., Xiao, L. D., & De Bellis, A. (2016). First-time stroke survivors and caregivers’ perceptions of being engaged in rehabilitation. *Journal of Advanced Nursing*, *72*(1). https://doi.org/10.1111/jan.12819

Clarke, V., & Braun, V. (2017). Thematic analysis. *The Journal of Positive Psychology*, *12*(3), 297–298.

Code, C., Hemsley, G., & Herrmann, M. (1999). The emotional impact of aphasia. *Seminars in Speech and Language*, *20*(1), 19–31. https://doi.org/10.1055/s-2008-1064006

Code, C, & Petheram, B. (2011). Delivering for aphasia. *International Journal Of Speech-Language Pathology*, *13*(1), 3–10.

Code, C., & Herrmann, M. (2003). The relevance of emotional and psychosocial factors in aphasia to rehabilitation. *Neuropsychological Rehabilitation*, *13*(1–2), 109–132. https://doi.org/10.1080/09602010244000291

Code, C., & Petheram, B. (2011). Delivering for aphasia. *International Journal of Speech-Language Pathology*, *13*(1), 3–10. https://doi.org/10.3109/17549507.2010.520090

Conneeley, A. L. (2004). Interdisciplinary collaborative goal planning in a post-acute neurological setting: a qualitative study. *British Journal of Occupational Therapy*, *67*(6), 248–255. Retrieved from https://search.proquest.com/docview/57195963?accountid=13828

Corbin, J., & Strauss, A. (2014). *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*. SAGE Publications. Retrieved from https://books.google.co.uk/books?id=hZ6kBQAAQBAJ

Craciun, C., & Flick, U. (2016). I wonder if robots will take care of me when I am old: Positive aging representations of professionals working in health promotion services. *Journal of Health Psychology*, *21*(12), 2872–2881.

Creswell, J. W. (2007). *Qualitative inquiry & research design : choosing among five approaches*. (J. W. Creswell, Ed.), *Qualitative inquiry and research design* (2nd ed.). Thousand Oaks: Thousand Oaks : Sage Publications, c2007.

Cruice, M., Worrall, L., & Hickson, L. (2006). Perspectives of quality of life by people with aphasia and their family: Suggestions for successful living. *Topics in Stroke Rehabilitation*, *13*(1), 14–24. https://doi.org/10.1310/4JW5-7VG8-G6X3-1QVJ

Cypress, B. S. (2017). Rigor or reliability and validity in qualitative research: Perspectives, strategies, reconceptualization, and recommendations. *Dimensions of Critical Care*

Nursing, 36(4), 253–263. https://doi.org/10.1097/DCC.0000000000000253

Dalemans, R. J. P., de Witte, L., Wade, D., & van den Heuvel, W. (2009). Social participation through the eyes of people with aphasia. *International Journal of Language & Communication Disorders.* [London] : https://doi.org/10.3109/13682820903223633

Dalton, C., Farrell, R., De Souza, A., Wujanto, E., McKenna-Slade, A., Thompson, S., … Greenwood, R. (2012). Patient inclusion in goal setting during early inpatient rehabilitation after acquired brain injury. *Clinical Rehabilitation*, *26*(2), 165–173. https://doi.org/10.1177/0269215511405230

Damico, J. S., Simmons-Mackie, N., Oelschlaeger, M., Elman, R., & Armstrong, E. (1999). Qualitative methods in aphasia research: basic issues. *Aphasiology, 13*(9–11), 651–665. https://doi.org/10.1080/026870399401768

Davidson, B., Howe, T., Worrall, L., Hickson, L., & Togher, L. (2008). Social participation for older people with aphasia: The impact of communication disability on friendships. *Topics in Stroke Rehabilitation*, *15*(4), 325–340. https://doi.org/10.1310/tsr1504-325

Davidson, B., Worrall, L., & Hickson, L. (2003). Identifying the communication activities of older people with aphasia: Evidence from naturalistic observation. *Aphasiology*, *17*(3), 243–264.

Davis, G. A. (George A. (1993). *A survey of adult aphasia and related language disorders* (2nd ed.). Englewood Cliffs, N.J. : London: Prentice Hall ; Prentice-Hall International.

de Jong-Hagelstein, M., van de Sandt-Koenderman, W. M. E., Prins, N. D., Dippel, D. W. J., Koudstaal, P. J., & Visch-Brink, E. G. (2011). Efficacy of early cognitive–linguistic treatment and communicative treatment in aphasia after stroke: a randomised controlled trial (RATS-2). *Journal of Neurology, Neurosurgery & Psychiatry*, *82*(4). Retrieved from http://jnnp.bmj.com/content/82/4/399.full.pdf

Denscombe, M. (1998). *The good research guide for small-scale social research projects*. Buckingham: Open University Press.

Denscombe, M. (2003). *The Good research guide for small-scale social research projects* (2nd ed.). Maidenhead: Maidenhead : Open University Press, 2003.

Denzin, N. K., & Lincoln, Y. S. (Eds.). (2008). *Strategies of qualitative inquiry* (3rd ed.). London: London : SAGE, c2008.

Devers, K., & Frankel, R. (2000). Study design in qualitative research--2: Sampling and data collection strategies. *Education for Health*, *13*(2). Retrieved from http://search.proquest.com/docview/214066906/

Duchan, J., & Black, M. (2001). Progressing toward life goals: A person-centered approach to evaluating therapy. *Topics in Language Disorders*, *22*(1), 37–49.

Duchan, J. F. (2004). Where is the person in the ICF? *International Journal of Speech-Language Pathology*. https://doi.org/10.1080/14417040410001669444

El Sayed, M. M., Adeuja, A. O. G., El-Nahrawy, E., & Olaish, M. A. M. (1999). Characteristics of stroke in Hofuf, Saudi Arabia. *Annals of Saudi Medicine*, *19*, 27–31.

Elman, R. J. (2006). *Group treatment of neurogenic communication disorders: The expert clinician's approach*. Plural Publishing.

Elman, R. J. (2016). Aphasia centers and the life participation approach to aphasia: A paradigm shift. *Topics in Language Disorders*, *36*(2), 154–167. https://doi.org/10.1097/TLD.0000000000000087

Eze, J., Ezemba, N., & Adamu, Y. (2010). A study of extracranial aneurysms at UNTH in Enugu, Nigeria. *Nigerian Journal of Clinical Practice*, *13*(3), 272–275. Retrieved from http://www.njcponline.com/article.asp?issn=1119-3077;year=2010;volume=13;issue=3;spage=272;epage=275;aulast=Eze;type=0

Fahy, P. (2001). Addressing some Common Problems in Transcript Analysis. *International Review of Research in Open and Distance Learning*, *1*(2). Retrieved from http://search.proquest.com/docview/1634545725/

Ferguson, A., Worrall, L., Davidson, B., Hersh, D., Howe, T., & Sherratt, S. (2010). Describing the experience of aphasia rehabilitation through metaphor. *Aphasiology*, *24*(6–8), 685–696. https://doi.org/10.1080/02687030903438508

Flick, U. (2006). *An introduction to qualitative research* (3rd ed.). London: SAGE.

Flick, U. (2008a). *Designing Qualitative Research [electronic resource]. Qualitative Research Kit*. London: London : SAGE Publications, 2008.

Flick, U. (2008b). *Managing Quality in Qualitative Research [electronic resource]. Qualitative Research Kit*. London: London : SAGE Publications, 2008.

Flick, U. (2014). *An introduction to qualitative research* (Fifth edit). Los Angeles : Sage, 2014.

Flick, U., Garms-Homolová, V., & Röhnsch, G. (2012). "And mostly they have a need for sleeping pills": Physicians' views on treatment of sleep disorders with drugs in nursing homes. *Journal of Aging Studies*, *26*(4), 484–494. https://doi.org/10.1016/j.jaging.2012.07.001

Fotiadou, D., Northcott, S., Chatzidaki, A., & Hilari, K. (2014). Aphasia blog talk: How does stroke and aphasia affect a person's social relationships? *Aphasiology*, *28*(11), 1281–1300. https://doi.org/10.1080/02687038.2014.928664

Furfey, P. H. (1947). The Sampling Problem. *The American Catholic Sociological Review*, *8*(4), 258–265.

Gauggel, S., & Fischer, S. (2001). The effect of goal setting on motor performance and motor learning in brain-damaged patients. *Neuropsychological Rehabilitation*, *11*(1), 33–44. https://doi.org/10.1080/09602010042000150

Gauggel, S., Leinberger, R., & Richardt, M. (2001). Goal setting and reaction time performance in brain-damaged patients. *Journal of Clinical and Experimental Neuropsychology*, *23*(3), 351–361. https://doi.org/10.1076/jcen.23.3.351.1178

Gauggel, S., & Billino, J. (2002). The effects of goal setting on the arithmetic performance of brain-damaged patients. *Archives of Clinical Neuropsychology*, *17*(3), 283–294. https://doi.org/10.1016/S0887-6177(01)00113-5

Gauggel, S., Hoop, M., & Werner, K. (2002). Assigned versus self-set goals and their impact on the performance of brain-damaged patients. *Journal of Clinical and Experimental Neuropsychology*, *24*(8), 1070–1080. https://doi.org/10.1076/jcen.24.8.1070.8377

Goren, A., Montgomery, W., Kahle-Wrobleski, K., Nakamura, T., & Ueda, K. (2016). Impact of caring for persons with Alzheimer's disease or dementia on caregivers' health outcomes: Findings from a community based survey in Japan. *BMC Geriatrics*, *16*(1), 1–12. https://doi.org/10.1186/s12877-016-0298-y

Giaquinto, S., Spiridigliozzi, C., & Caracciolo, B. (2007). Can faith protect from emotional distress after stroke? *Stroke*, *38*(3), 993–997. https://doi.org/10.1161/01.STR.0000257996.26950.59

Gibbs, G. (2007). *Analyzing qualitative data*. (U. Flick, Ed.), *Qualitative research kit*. London: London : SAGE, 2007. Retrieved from http://methods.sagepub.com.eresources.shef.ac.uk/book/analyzing-qualitative-data

Gillespie, A., Murphy, J., & Place, M. (2010). Divergences of perspective between people with aphasia and their family caregivers. *Aphasiology*, *24*(12), 1559–1575. https://doi.org/10.1080/02687038.2010.500810

Glaser, B. (1992). *Basics of grounded theory analysis : emergence vs forcing*. Mill Valley, Ca: Mill Valley, Ca : Sociology Press, 1992.

Glaser, B., & Strauss, A. L. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Aldine. Retrieved from https://books.google.co.uk/books?id=oUxEAQAAIAAJ

Glaser, B. (2002). Conceptualization: On Theory and Theorizing Using Grounded Theory. *International Journal of Qualitative Methods*, *1*(2), 23–38. https://doi.org/10.1177/160940690200100203

Glaser, B. (1978). *Theoretical sensitivity : advances in the methodology of grounded theory*. Mill Valley, Calif.: The Sociology Press.

Glaser, B. (1999). *The discovery of grounded theory : strategies for qualitative research* (Reprint.). New York: Aldine Transaction.

Glazier, S. R., Schuman, J., Keltz, E., Vally, A., & Glazier, R. H. (2004). Taking the Next Steps in Goal Ascertainment: A Prospective Study of Patient, Team, and Family Perspectives Using a Comprehensive Standardized Menu in a Geriatric Assessment and Treatment Unit. *Journal of the American Geriatrics Society*, *52*(2), 284–289.

https://doi.org/10.1111/j.1532-5415.2004.52072.x

Moskowitz, G. "The Representation and Regulation of Goals." Goal-Directed Behavior. Taylor and Francis, 2012. 1-48. Web.

Gollwitzer, P. M. (1993). Goal achievement: The role of intentions. *European Review of Social Psychology*, *4*(1), 141–185.

Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, *24*(2), 105–112.

Grawburg, M., Howe, T., Worrall, L., & Scarinci, N. (2012). A systematic review of the positive outcomes for family members of people with aphasia. *Evidence-Based Communication Assessment and Intervention*. https://doi.org/10.1080/17489539.2012.739383

Grawburg, M., Howe, T., Worrall, L., & Scarinci, N. (2013a). A qualitative investigation into third-party functioning and third-party disability in aphasia: Positive and negative experiences of family members of people with aphasia. *Aphasiology*, *27*(7), 828–848. https://doi.org/10.1080/02687038.2013.768330

Grawburg, M., Howe, T., Worrall, L., & Scarinci, N. (2013b). Third-party disability in family members of people with aphasia: A systematic review. *Disability and Rehabilitation*, *35*(16), 1324–1341. https://doi.org/10.3109/09638288.2012.735341

Grawburg, M., Howe, T., Worrall, L., & Scarinci, N. (2014). Describing the impact of aphasia on close family members using the ICF framework. *Disability and Rehabilitation*. https://doi.org/10.3109/09638288.2013.834984

Grawburg, M., Howe, T., Worrall, L., & Scarinci, N. (2019). Family-Centered Care in Aphasia: Assessment of Third-Party Disability in Family Members with the Family Aphasia Measure of Life Impact. *Topics in Language Disorders*, *39*(1), 29–54. https://doi.org/10.1097/TLD.0000000000000176

Greene, J., & McClintock, C. (1985). Triangulation in Evaluation: Design and Analysis Issues. *Evaluation Review*, *9*(5), 523–545.

Greenwood, N., & Mackenzie, A. (2010). Informal caring for stroke survivors: Meta-ethnographic review of qualitative literature. *Maturitas*, *66*(3), 268–276. https://doi.org/10.1016/j.maturitas.2010.03.017

Groger, L., Mayberry, P. S., & Straker, J. K. (1999). What We Didn't Learn Because of Who Would Not Talk to Us. *Qualitative Health Research*, *9*(6), 829–835.

Grohn, B., Worrall, L., Simmons-Mackie, N., & Hudson, K. (2014). Living successfully with aphasia during the first year post-stroke: A longitudinal qualitative study. *Aphasiology, 28*(12). https://doi.org/10.1080/02687038.2014.935118

Haley, K., Helm-Estabrooks, N., Caignon, D., Womack, J., & McCulloch, K. (2009). Self-Determination & Life Activity Goals for People With Aphasia. *2009 Convention of the American Speech-Language-Hearing Association (ASHA 2009)*. Retrieved from http://search.proquest.com/docview/42162365?accountid=13828

Haley, K. L., Womack, J., Helm-Estabrooks, N., Lovette, B., & Goff, R. (2013). Supporting Autonomy for People with Aphasia: Use of the Life Interests and Values (LIV) Cards. *Topics in Stroke Rehabilitation*, *20*(1), 22–35. https://doi.org/10.1310/tsr2001-22

Hallé, M. C., & Le Dorze, G. (2014). Understanding significant others' experience of aphasia and rehabilitation following stroke. *Disability and Rehabilitation, 36*(21), 1774–1782.

Hallé, M. C., Le Dorze, G., & Mingant, A. (2014). Speech-language therapists' process of including significant others in aphasia rehabilitation. *International Journal of Language & Communication Disorders*. [London] : https://doi.org/10.1111/1460-6984.12108

Hallé, M. C., Duhamel, F., & Le Dorze, G. (2011). The daughter-mother relationship in the presence of aphasia: How daughters view changes over the first year poststroke. *Qualitative Health Research*, *21*(4), 549–562. https://doi.org/10.1177/1049732310391274

Handbook of qualitative research. (1994). Thousand Oaks, Calif ; London: Sage.

Hanger, H. C., & Mulley, G. P. (1993). Questions people ask about stroke. *Stroke*, *24*(4), 536–538. https://doi.org/10.1161/01.STR.24.4.536

Hanger, H. C., Walker, G., Paterson, L. A., McBride, S., & Sainsbury, R. (1998). What do patients and their carers want to know about stroke? A two-year follow-up study. *Clinical Rehabilitation*, *12*(1), 45–52. https://doi.org/10.1191/026921598668677675

Harper, D., & Thompson, A. R. (2011). *Qualitative Research Methods in Mental Health and PsychotherapyA Guide for Students and Practitioners*. Wiley.

Harty, M., Griesel, M., & Van der Merwe, A. (2011). The ICF as a common language for rehabilitation goal-setting: Comparing client and professional priorities. *Health and Quality of Life Outcomes*, *9*. https://doi.org/10.1186/1477-7525-9-87

Hatry, H. P. (1994). Collecting data from agency records. *Handbook of Practical Program Evaluation*, 374–386.

Hebert, D., Lindsay, M. P., McIntyre, A., Kirton, A., Rumney, P. G., Bagg, S., Teasell, R. (2016). Canadian stroke best practice recommendations: Stroke rehabilitation practice guidelines, update 2015. *International Journal of Stroke*, *11*(4), 459–484. https://doi.org/10.1177/1747493016643553

Hennink, M. M. (2011). *Qualitative research methods*. (I. Hutter, A. Bailey, & I. (Inge) Hutter, Eds.). London : London .

Herbert, R., Haw, C., Brown, C., Gregory, E., & Brumfitt, S. (2012). *Accessible Information Guidelines*. Retrieved from https://www.stroke.org.uk/shop/product/accessible-information-guidelines

Hersh, D., Sherratt, S., Howe, T., Worrall, L., Davidson, B., & Ferguson, A. (2012a). An analysis of the “goal” in aphasia rehabilitation. *Aphasiology*, *26*(8), 971–984. https://doi.org/10.1080/02687038.2012.684339

Hersh, D., Worrall, L., Howe, T., Sherratt, S., & Davidson, B. (2012b). SMARTER goal setting in aphasia rehabilitation. *Aphasiology*, *26*(2), 220–233. https://doi.org/10.1080/02687038.2011.640392

Hersh, D. (2009). How do people with aphasia view their discharge from therapy? *Aphasiology*. [London] : https://doi.org/10.1080/02687030701764220

Hesamzadeh, A., Dalvandi, A., Bagher Maddah, S., Fallahi Khoshknab, M., & Ahmadi, F. (2015). Family adaptation to stroke: A metasynthesis of qualitative research based on double ABCX model. *Asian Nursing Research*, *9*(3), 177–184. https://doi.org/10.1016/j.anr.2015.03.005

Hickey, A., Holly, D., McGee, H., Conroy, R., & Shelley, E. (2012). Knowledge of stroke risk factors and warning signs in Ireland: Development and application of the Stroke Awareness Questionnaire (SAQ). *International Journal of Stroke*, *7*(4), 298–306. https://doi.org/10.1111/j.1747-4949.2011.00698.x

Hinckley, J., & Carr, T. (2005). Comparing the outcomes of intensive and non-intensive context-based aphasia treatment. *Aphasiology*, *19*(10–11), 965–974.

Hodson, R. (1999). *Analyzing documentary accounts [electronic resource]*. Thousand Oaks, Calif.: Sage Publications.

Holland, A. L, & Nelson, R. L. (2018). *Counseling in communication disorders: A wellness perspective*. Plural Publishing.

Holland, A. L. (1991). Pragmatic aspects of intervention in aphasia. *Journal of Neurolinguistics*, *6*(2), 197–211. https://doi.org/10.1016/0911-6044(91)90007-6

Holland, A. L. (1982). Observing functional communication of aphasic adults. *Journal of Speech and Hearing Disorders*, *47*(1), 50–56. https://doi.org/10.1044/jshd.4701.50

Holliday, R. C., Ballinger, C., & Playford, E. D. (2007). Goal setting in neurological rehabilitation: Patients' perspectives. *Disability and Rehabilitation*, *29*(5), 389–394. https://doi.org/10.1080/09638280600841117

Holliday, R C, Ballinger, C., & Playford, E. D. (2007). Goal setting in neurological rehabilitation: Patients' perspectives. *Disability & Rehabilitation, 2007, Vol.29(5), p.389-394*, *29*(5), 389–394. https://doi.org/10.1080/09638280600841117

Holliday, Rosaline C, Antoun, M., & Playford, E. D. (2005). A Survey of Goal-Setting Methods Used in Rehabilitation. *Neurorehabilitation and Neural Repair*, *19*(3), 227–231.

Hopper, T., Holland, A., & Rewega, M. (2002). Conversational coaching: Treatment outcomes and future directions. *Aphasiology*, *16*(7), 745–761. https://doi.org/10.1080/02687030244000059

House, A., Dennis, M., Hawton, K., & Warlow, C. (1989). Methods of identifying mood disorders in stroke patients: experience in the Oxfordshire Community Stroke Project. *Age and Ageing*, *18*(6).

Howe, T. J., Worrall, L., Hickson, L. M. H. (2008). Interviews with people with aphasia: Environmental factors that influence their community participation. *Aphasiology*. [London] : https://doi.org/10.1080/02687030701640941

Howe, T., Davidson, B., Worrall, L., Hersh, D., Ferguson, A., Sherratt, S., & Gilbert, J. (2012). 'You needed to rehab … families as well': family members' own goals for aphasia rehabilitation. *International Journal of Language & Communication Disorders*, *47*(5), 511–521. https://doi.org/10.1111/j.1460-6984.2012.00159.x

Hsieh, H. F., & Shannon, S. E. (2005). Three Approaches to Qualitative Content Analysis. *Qualitative Health Research*, *15*(9), 1277–1288.

Huby, G., Stewart, J., Tierney, A., & Rogers, W. (2004). Planning older people's discharge from acute hospital care: Linking risk management and patient participation in decision-making. *Health, Risk and Society*, *6*(2), 115–132. https://doi.org/10.1080/1369857042000219797

Humble, Á. (2015). Guide to Transcribing. *Retrieved from Mount Saint Vincent University: Www. Msvu. ca/Site/Media/Msvu/GuideTranscribing. Pdf*.

Humphreys, I., Thomas, S., Phillips, C., & Lincoln, N. (2015). Cost analysis of the Communication and Low Mood (CALM) randomised trial of behavioural therapy for stroke patients with aphasia. *Clinical Rehabilitation*, *29*(1), 30–41.

Imam, I., & Olorunfemi, G. (2005). Clinical Diagnosis of Stroke: Need for Audit. *Annals of African Medicine*, *3*(4). Retrieved from http://www.bioline.org.br/abstract?id=am04043

Immenschuh, U. (2005). "My arm and leg - they are just sleeping". Perspectives of younger people on their experienes of having a stoke.

International Classification of Functioning , Disability and. (2001).

Israel, M. (2006). *Research Ethics for Social Scientists [electronic resource]*. (I. Hay, Ed.), *RESEARCH ETHICS FOR SOCIAL SCIENTISTS*. London: London : SAGE

Publications, 2006.

Jensen, L. R., Løvholt, A. P., Sørensen, I. R., Blüdnikow, A. M., Iversen, H. K., Hougaard, A., … Forchhammer, H. B. (2015). Implementation of supported conversation for communication between nursing staff and in-hospital patients with aphasia. *Aphasiology*, *29*(1), 57–80. https://doi.org/10.1080/02687038.2014.955708

Matos, M. A. C., Jesus, L. M. T., & Cruice, M. (2014). Consequences of stroke and aphasia according to the ICF domains: Views of Portuguese people with aphasia, family members and professionals. *Aphasiology*. [London] : https://doi.org/10.1080/02687038.2014.906561

Johansson, M. B., Carlsson, M., & Sonnander, K. (2012). Communication difficulties and the use of communication strategies: from the perspective of individuals with aphasia. *International Journal of Language & Communication Disorders*. [London] : https://doi.org/10.1111/j.1460-6984.2011.00089.x

Jones, F., Mandy, A., & Partridge, C. (2008). Reasons for recovery after stroke: A perspective based on personal experience. *Disability & Rehabilitation, 2008, Vol.30(7), p.507-516*, *30*(7), 507–516.

Jones, S. P., Jenkinson, A. J., Leathley, M. J., & Watkins, C. L. (2009). Stroke knowledge and awareness: An integrative review of the evidence. *Age and Ageing*, *39*(1), 11–22. https://doi.org/10.1093/ageing/afp196

Kagan, A, Black, S. E., Duchan, F. J., Simmons-Mackie, N., & Square, P. (2001). Training volunteers as conversation partners using "Supported Conversation for Adults with Aphasia" (SCA): a controlled trial. *Journal of Speech, Language, and Hearing Research : JSLHR*, *44*(3), 624.

Kagan, Aura. (1998). Supported conversation for adults with aphasia: methods and resources for training conversation partners. *Aphasiology*, *12*(9), 816–830. https://doi.org/10.1080/02687039808249575

Katbamna, S., Manning, L., Mistri, A., Johnson, M., & Robinson, T. (2017). Balancing satisfaction and stress: carer burden among White and British Asian Indian carers of stroke survivors. *Ethnicity and Health*, *22*(4), 425–441. https://doi.org/10.1080/13557858.2016.1244740

Khoja, M. A., & Sheeshah, H. (2018). The human right to communicate: A survey of available services in Saudi Arabia. *International Journal of Speech-Language Pathology*, *20*(1), 102–107. https://doi.org/10.1080/17549507.2018.1428686

King Fahad Medical City. (n.d.). Retrieved 10 April 2020 from https://www.kfmc.med.sa/EN/Pages/Home.aspx

Kim, Y. (2011). The Pilot Study in Qualitative Inquiry. *Qualitative Social Work*, *10*(2), 190–206. Retrieved from http://search.proquest.com/docview/902082728/

Kiresuk, T. J., & Sherman, R. E. (2016). Goal Attainment Scaling: A General Method for Evaluating Comprehensive Community Mental Health Programs, *4*(6), 443–453. https://doi.org/10.1007/BF01530764

Kitson, A. L., Dow, C., Calabrese, J. D., Locock, L., & Athlin, Å. M. (2013). Stroke survivors' experiences of the fundamentals of care: A qualitative analysis. *International Journal of Nursing Studies*, *50*(3), 392–403. https://doi.org/10.1016/j.ijnurstu.2012.09.017

Knollman-Porter, K., Wallace, S. E., Hux, K., Brown, J., & Long, C. (2015). Reading experiences and use of supports by people with chronic aphasia. *Aphasiology*, 1–25.

Kokorelias, K. M., Lu, F. K. T., Santos, J. R., Xu, Y., Leung, R., & Cameron, J. I. (2019). "Caregiving is a full-time job" impacting stroke caregivers' health and well-being: A qualitative meta-synthesis. *Health and Social Care in the Community*, (October 2019), 325–340. https://doi.org/10.1111/hsc.12895

Kümmerer, D., Hartwigsen, G., Kellmeyer, P., Glauche, V., Mader, I., Klöppel, S., Saur, D. (2013). Damage to ventral and dorsal language pathways in acute aphasia. *Brain*, *136*(2), 619–629.

Kurasaki, K. S. (2000). Intercoder Reliability for Validating Conclusions Drawn from Open-Ended Interview Data. *Field Methods*, *12*(3), 179–194.

Kvale, S. (2007). *Doing interviews*. (U. Flick, Ed.), *Qualitative research kit*. London: London : SAGE, 2007.

Laliberté, M. P., Alary Gauvreau, C., & Le Dorze, G. (2016). A pilot study on how speech-language pathologists include social participation in aphasia rehabilitation. *Aphasiology*, *30*(10), 1117–1133. https://doi.org/10.1080/02687038.2015.1100708

Laver, K., Halbert, J., Stewart, M., & Crotty, M. (2010). Patient Readiness and Ability to Set Recovery Goals During the First 6 Months After Stroke. *Journal of Allied Health*, *39*(4), E149-54. Retrieved from https://search.proquest.com/docview/874211107?accountid=13828

Lawler, J., Dowswell, G., Hearn, J., Forster, A., & Young, J. (1999). Recovering from stroke: A qualitative investigation of the role of goal setting in late stroke recovery. *Journal of Advanced Nursing*, *30*(2), 401–409. https://doi.org/10.1046/j.1365-2648.1999.01086.x

Lawrence, M. (2010). Qualitative Review of the Literature. *Stroke*, *19*(4), 241–248.

Lawton, M., Haddock, G., Conroy, P., Serrant, L., & Sage, K. (2018). People with aphasia's perception of the therapeutic alliance in aphasia rehabilitation post stroke: a thematic analysis. *Aphasiology*, *32*(12), 1397–1417.

Le Dorze, G., & Signori, F. H. (2010). Needs, barriers and facilitators experienced by spouses of people with aphasia. *Disability and Rehabilitation*, *32*(13), 1073–1087. https://doi.org/10.3109/09638280903374121

Le Dorze, G., Tremblay, V., & Croteau, C. (2009). A qualitative longitudinal case study of a daughter's adaptation process to her father's aphasia and stroke. *Aphasiology*, *23*(4), 483–502. https://doi.org/10.1080/02687030801890909

Leach, E, Cornwell, P., Fleming, J., & Haines, T. (2010). Patient centered goal-setting in a subacute rehabilitation setting. *Disability and Rehabilitation*, *32*(2), 159–172. https://doi.org/10.3109/09638280903036605

Lee, J., Yoshida, M., & Thompson, C. (2015). Grammatical Planning Units During Real-Time Sentence Production in Speakers With Agrammatic Aphasia and Healthy Speakers. *Journal Of Speech Language And Hearing Research*, *58*(4), 1182–1194.

Levack, W., Siegert, R. J., Dean, S. G., & McPherson, K. M. (2009). Goal planning for adults with acquired brain injury: How clinicians talk about involving family. *Brain Injury, 23*(3), 192–202. https://doi.org/10.1080/02699050802695582

Levack, W., Dean, S., Mcpherson, K., & Siegert, R. (2006). How clinicians talk about the application of goal planning to rehabilitation for people with brain injury-variable interpretations of value and purpose. *Brain Injury, 20*(13–14), 1439–1449. https://doi.org/10.1080/02699050601118422

Levack, W., Dean, S. G., Siegert, R. J., & McPherson, K. M. (2011). Navigating patient-centered goal setting in inpatient stroke rehabilitation: How clinicians control the process to meet perceived professional responsibilities. *Patient Education and Counseling, 85*(2), 206–213. https://doi.org/10.1016/j.pec.2011.01.011

Levack, W., Taylor, K., Siegert, R. J., Dean, S. G., McPherson, K. M., & Weatherall, M. (2006). Is goal planning in rehabilitation effective? A systematic review. *Clinical Rehabilitation, 20*(9), 739–755. https://doi.org/10.1177/0269215506070791

Levack, W., Weatherall, M., Hay-smith, Ej., Dean, S., Mcpherson, K., & Siegert, R. (2016). Goal setting and strategies to enhance goal pursuit in adult rehabilitation: summary of a Cochrane systematic review and meta-analysis.

Levinson, W., Kao, A., Kuby, A., & Thisted, R. A. (2005). Not all patients want to participate in decision making. *Journal Of General Internal Medicine*, *20*(6), 531–535. https://doi.org/10.1111/j.1525-1497.2005.0088.x

Lewis, M. K. (2001). Islam and accounting. *Accounting Forum, 25*(2), 103–127. https://doi.org/10.1111/1467-6303.00058

Lincoln, Y., & Guba, E. (1985). *Naturalistic inquiry*. Beverly Hills, Calif. ; London: Sage.

Lloyd, A., Roberts, A. R., & Freeman, J. A. (2014). “Finding a Balance” in Involving Patients in Goal Setting Early After Stroke: A Physiotherapy Perspective. *Physiotherapy Research International*, *19*(3), 147–157. https://doi.org/10.1002/pri.1575

Lock, S., Wilkinson, R., Bryan, K., Maxim, J., Edmundson, A., Bruce, C., & Moir, D. (2001). Supporting Partners of People with Aphasia in Relationships and Conversation

(SPPARC). *International Journal of Language & Communication Disorders*, *36*(s1), 25–30. https://doi.org/10.3109/13682820109177853

Locke, E. A., & Latham, G. P. (2002). Building a practically useful theory of goal setting and task motivation. A 35-year odyssey. *The American Psychologist*, *57*(9), 705–717. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=med4&NEWS=N&AN=12237980

López-Espuela, F., González-Gil, T., Amarilla-Donoso, J., Cordovilla-Guardia, S., Portilla-Cuenca, J. C., & Casado-Naranjo, I. (2018). Critical points in the experience of spouse caregivers of patients who have suffered a stroke. A phenomenological interpretive study. *PLoS ONE*, *13*(4), 1–16. https://doi.org/10.1371/journal.pone.0195190

Lou, S., Carstensen, K., Jørgensen, C. R., & Nielsen, C. P. (2017). Stroke patients' and informal carers' experiences with life after stroke: an overview of qualitative systematic reviews. *Disability and Rehabilitation*, *39*(3), 301–313. https://doi.org/10.3109/09638288.2016.1140836

Luck, A. M., & Rose, M. L. (2007). Interviewing people with aphasia: Insights into method adjustments from a pilot study. *Aphasiology*, *21*(2), 208–224. https://doi.org/10.1080/02687030601065470

Luker, J., Murray, C., Lynch, E., Bernhardsson, S., Shannon, M., & Bernhardt, J. (2017). Carers' Experiences, Needs, and Preferences During Inpatient Stroke Rehabilitation: A Systematic Review of Qualitative Studies. *Archives of Physical Medicine and Rehabilitation*, *98*(9), 1852--1862.e13.

Mack, L. (2010). The philosophical underpinnings of educational research.

Mackenzie, C., Paton, G., Kelly, S., Brady, M., & Muir, M. (2012). The "Living with Dysarthria" Group: Implementation and Feasibility of a Group Intervention for People with Dysarthria Following Stroke and Family Members. *International Journal of Language & Communication Disorders*, *47*(6), 709–724. https://doi.org/10.1111/j.1460-6984.2012.00180.x

Maitra, K. K., & Erway, F. (2006). Perception of client-centered practice in occupational therapists and their clients. *American Journal of Occupational Therapy*, *60*(3), 298–310. Retrieved from https://www.scopus.com/inward/record.uri?eid=2-s2.0-33745090848&partnerID=40&md5=f03ec57a00db9ecd923c6af440cbef00

Majid, M. A. A., Othman, M., Mohamad, S. F., Lim, S. A. H., & Yusof, A. (2017). Piloting for interviews in qualitative research: Operationalization and lessons learnt. *International Journal of Academic Research in Business and Social Sciences*, *7*(4), 1073–1080.

Marshall, C. (2011). *Designing qualitative research*. (G. B. Rossman, Ed.) (5th ed.). Thousand Oaks: Thousand Oaks : Sage Publications, c2011.

Marshall, R. C., & Wright, H. H. (2007). Developing a clinician-friendly aphasia test. *American Journal of Speech-Language Pathology*, *16*(4).

Martin-Saez, M. M., & James, N. (2019). The experience of occupational identity disruption post stroke: a systematic review and meta-ethnography. *Disability and Rehabilitation*, *0*(0), 1–12. https://doi.org/10.1080/09638288.2019.1645889

Matos, Maria Assunção CJesus, L. M. T., & Cruice, M. (2014). Consequences of stroke and aphasia according to the ICF domains: Views of Portuguese people with aphasia, family members and professionals. *Aphasiology*. [London] : https://doi.org/10.1080/02687038.2014.906561

McClain, C. (2005). Collaborative rehabilitation goal setting. *Topics in Stroke Rehabilitation*, *12*(4), 56–60. https://doi.org/10.1310/ELB1-EGKF-QUQC-VFE9

McLellan, E., MacQueen, K. M., & Neidig, J. L. (2003). Beyond the qualitative interview: Data preparation and transcription. *Field Methods*, *15*(1), 63–84.

Michallet, B., Le Dorze, G., & Tétreault, S. (2001). The needs of spouses caring for severely aphasic persons. *Aphasiology*, *15*(8), 731–747. https://doi.org/10.1080/02687040143000087

Michallet, B., Tétreault, S., & Le Dorze, G. (2003). The consequences of severe aphasia on the spouses of aphasic people: A description of the adaptation process. *Aphasiology*, *17*(9), 835–859. https://doi.org/10.1080/02687030344000238

Mitchell, K., Skirton, H., & Monrouxe, L. (2011). Amelioration, regeneration, acquiescent and discordant: an exploration of narrative types and metaphor use in people with aphasia. *Disability & Society*, *26*(3), 321–335. Retrieved from http://search.proquest.com/docview/1038113240/

Saudi Ministry of Health. (2018). Statistical yearbook. retrieved form https://www.moh.gov.sa/en/Ministry/Statistics/book/Pages/default.aspx

Mohammed, E. G., Nur, M. A., Kurashi, N. Y., Ibrahim, E., & Ammar, K. (1996). Survival after stroke in saudis : a hospital based study. *Journal of Family & Community Medicine*, *3*(1).

Morris, M. A., Clayman, M. L., Peters, K. J., Leppin, A. L., & Leblanc, A. (2015). Patient-centered communication strategies for patients with aphasia: Discrepancies between what patients want and what physicians do. *Disability and Health Journal*, *8*(2), 208–215. https://doi.org/10.1016/j.dhjo.2014.09.007

Morse, J. M., Barrett, M., Mayan, M., Olson, K., & Spiers, J. (2002). Verification Strategies for Establishing Reliability and Validity in Qualitative Research. *International Journal of Qualitative Methods*, *1*(2), 13–22.

Mozeiko, J., Coelho, C. A., & Myers, E. B. (2016). The role of intensity in constraint-induced language therapy for people with chronic aphasia. *Aphasiology*, *30*(4), 339–363.

Mummery, C. J., Ashburner, J., Scott, S. K., & Wise, R. J. S. (1999). Functional neuroimaging of speech perception in six normal and two aphasic subjects. *The Journal of the Acoustical Society of America*, *106*(1), 449–457.

Murphy, J., & Boa, S. (2012). Using the WHO-ICF with Talking Mats to Enable Adults with Long-term Communication Difficulties to Participate in Goal Setting. *Augmentative and Alternative Communication*, *28*(1), 52–60. https://doi.org/10.3109/07434618.2011.653828

Murphy, J., & Oliver, T. (2013). The use of Talking Mats to support people with dementia and their carers to make decisions together. *Health & Social Care in the Community*. [Oxford, England] : https://doi.org/10.1111/hsc.12005

Murphy, J., Tester, S., Hubbard, G., Downs, M., & MacDonald, C. (2005). Enabling frail older people with a communication difficulty to express their views: the use of Talking Mats^{TM} as an interview tool. *Health & Social Care in the Community, 13*(2), 95–107. https://doi.org/10.1111/j.1365-2524.2005.00528.x

Nasr, N., Mawson, S., Wright, P., Parker, J., & Mountain, G. (2016). Exploring the Experiences of Living With Stroke Through Narrative: Stroke Survivors' Perspectives. *Global Qualitative Nursing Research, 3*. https://doi.org/10.1177/2333393616646518

Noble, H., & Smith, J. (2015). Issues of validity and reliability in qualitative research. *Evidence-Based Nursing*. https://doi.org/10.1136/eb-2015-102054

Norris, M., Allotey, P., & Barrett, G. (2012). "It burdens me": The impact of stroke in central Aceh, Indonesia. *Sociology of Health and Illness, 34*(6), 826–840. https://doi.org/10.1111/j.1467-9566.2011.01431.x

Northcott, S., Moss, B., Harrison, K., & Hilari, K. (2016). A systematic review of the impact of stroke on social support and social networks: Associated factors and patterns of change. *Clinical Rehabilitation*, *30*(8), 811–831. https://doi.org/10.1177/0269215515602136

Nyrop, R. (1993). *Saudi Arabia: a country study*. Federal Research Division,. Retrieved from http://hdl.handle.net/2027/mdp.39015028922667

Oppong, S. H. (2013). The problem of sampling in qualitative research. *Asian Journal of Management Sciences and Education*, *2*(2), 202–210.

Papathanasiou, I. (2017). *Aphasia and related neurogenic communication disorders*. (P. Coppens, Ed.) (Second edi). Burlington, MA: Burlington, MA : Jones & Bartlett Learning, 2017.

Parr, S. (2007). Living with severe aphasia: Tracking social exclusion. *Aphasiology*, *21*(1), 98–123.

Parr, S. (2001). Psychosocial aspects of aphasia: Whose perspectives? *Folia Phoniatrica et Logopaedica*, *53*(5), 266–288. https://doi.org/10.1159/000052681

Parsons, J. G. M., Plant, S. E., Slark, J., & Tyson, S. F. (2016). How active are patients in setting goals during rehabilitation after stroke? A qualitative study of clinician perceptions. *Disability and Rehabilitation*, 1–8. Retrieved from https://search.proquest.com/docview/1842545630?accountid=13828

Perry, S. (2001). Appropriate use of pilot studies. *Journal Of Nursing Scholarship*, *33*(2), 107.

Pettit, L., Tönsing, K. M., & Dada, S. (2016). The perspectives of adults with aphasia and their team members regarding the importance of nine life areas for rehabilitation: a pilot investigation. *Top Stroke Rehabil*, 1–8. https://doi.org/10.1080/10749357.2016.1207148

Petruzzi, A., Finocchiaro, C. Y., Lamperti, E., & Salmaggi, A. (2013). Living with a brain tumor: Reaction profiles in patients and their caregivers. *Supportive Care in Cancer*, *21*(4), 1105–1111. https://doi.org/10.1007/s00520-012-1632-3

Pike, C., Kritzinger, A., & Pillay, B. (2017). Social participation in working-age adults with aphasia: An updated systematic review. *Topics in Stroke Rehabilitation*, *24*(8), 627–639. https://doi.org/10.1080/10749357.2017.1366012

Plant, S., & Tyson, S. F. (2018). A multicentre study of how goal-setting is practised during inpatient stroke rehabilitation. *Clinical Rehabilitation*, *32*(2). https://doi.org/10.1177/0269215517719485

Plant, S., Tyson, S. F., Kirk, S., & Parsons, J. (2016). What are the barriers and facilitators to goal-setting during rehabilitation for stroke and other acquired brain injuries? A systematic review and meta-synthesis. *Clinical Rehabilitation*, *30*(9), 921–930. https://doi.org/10.1177/0269215516655856

Playford, E. D., Dawson, L., Limbert, V., Smith, M., Ward, C. D., & Wells, R. (2000). Goal-setting in rehabilitation: report of a workshop to explore professionals' perceptions of goal-setting. *Clinical Rehabilitation*, *14*(5), 491–496.

Playford, E. D., Siegert, R., Levack, W., & Freeman, J. (2009). Areas of consensus and controversy about goal setting in rehabilitation: a conference report. *Clinical Rehabilitation*, *23*(4), 334–344. https://doi.org/10.1177/0269215509103506

Poland, B. D. (1995). Transcription Quality as an Aspect of Rigor in Qualitative Research. *Qualitative Inquiry*, *1*(3), 290–310.

Ponterotto, J. G. (2005). Qualitative research in counseling psychology: A primer on research paradigms and philosophy of science. *Journal of Counseling Psychology*, *52*(2), 126.

Pound, C., Parr, S., & Duchan, J. (2001). Using partners' autobiographical reports to develop, deliver, and evaluate services in aphasia. *Aphasiology*, *15*(5), 477–493.

Power, E., Anderson, A., & Togher, L. (2011). Applying the WHO ICF framework to communication assessment and goal setting in Huntington's Disease: A case discussion. *Journal of Communication Disorders*, *44*(3), 261–275. https://doi.org/10.1016/j.jcomdis.2010.12.004

Power, E., Thomas, E., Worrall, L., Rose, M., Togher, L., Nickels, L., Clarke, K. (2015). Development and validation of Australian aphasia rehabilitation best practice statements using the RAND/UCLA appropriateness method. *BMJ Open*, *5*(7). https://doi.org/10.1136/bmjopen-2015-007641

Prescott, S., Fleming, J., & Doig, E. (2015). Goal setting approaches and principles used in rehabilitation for people with acquired brain injury: A systematic scoping review. *Brain Injury*, *29*(13–14), 1515–1529. https://doi.org/10.3109/02699052.2015.1075152

Purdy, M., & Hindenlang, J. (2005). Educating and training caregivers of persons with aphasia. *Aphasiology*, *19*(3–5), 377–388. https://doi.org/10.1080/02687030444000822

Purves, B. A. (2009). The complexities of speaking for another. *Aphasiology*. [London] : https://doi.org/10.1080/02687030802514946

Qari, F. A. (2001). Profile of stroke in a teaching university hospital in the western region. *Neurosciences (Riyadh, Saudi Arabia)*, *6*(1).

Rassool, G. H. (2000). The crescent and Islam: Healing, nursing and the spiritual dimension. Some considerations towards an understanding of the Islamic perspectives on caring. *Journal of Advanced Nursing*, *32*(6), 1476–1484. https://doi.org/10.1046/j.1365-2648.2000.01614.x

Rcslt Resource Manual for Commissioning and Planning Services for SLCN. (2014), *2009*.

Richards, L. (2005). *Handling qualitative data : a practical guide*. London: London : SAGE Publications, 2005.

Riessman, C. K. (2008). *Narrative methods for the human sciences*. Los Angeles, Calif. : Los Angeles, Calif. .

Ritchie, J., Ritchie, J., Lewis, J., McNaughton Nicholls, C., Ormston, R., & Nicholls, C. M. (Eds.). (2014). *Qualitative research practice : a guide for social science students and researchers.* (Second edi). Los Angeles : SAGE, 2014.

Robert, A. A., & Zamzami, M. M. (2014). Stroke in Saudi Arabia: a review of the recent literature. *The Pan African Medical Journal*, *17*, 14. https://doi.org/10.11604/pamj.2014.17.14.3015

Robinson-Smith, G. (2002). Prayer after Stroke:Its Relationship to Quality of Life. *Journal of Holistic Nursing*, *20*(4), 352–366. https://doi.org/10.1177/089801002237592

Robson, C., & McCartan, K. (2016). *Real world research*. John Wiley & Sons.

Rodriguez, H. P., Anastario, M. P., Frankel, R. M., Odigie, E. G., Rogers, W. H., Von Glahn, T., & Safran, D. G. (2008). Can teaching agenda-setting skills to physicians improve clinical interaction quality? A controlled intervention. *BMC Medical Education*, *8*, 1–7. https://doi.org/10.1186/1472-6920-8-3

Rohde, A., Townley-O’Neill, K., Trendall, K., Worrall, L., & Cornwell, P. (2012). A comparison of client and therapist goals for people with aphasia: A qualitative exploratory study. *Aphasiology*, *26*(10), 1298–1315. https://doi.org/10.1080/02687038.2012.706799

Rose, A., Rosewilliam, S., & Soundy, A. (2017). Shared decision making within goal setting in rehabilitation settings: A systematic review. *Patient Education and Counseling*, *100*(1), 65–75. https://doi.org/10.1016/j.pec.2016.07.030

Rose, M. L., & Luck, A. M. (2007). Interviewing people with aphasia: Insights into method adjustments from a pilot study. *Aphasiology*. [London] : https://doi.org/10.1080/02687030601065470

Rose, T. A., Worrall, L. E., Hickson, L. M., & Hoffmann, T. C. (2011). Aphasia friendly written health information: content and design characteristics. *International Journal of Speech-Language Pathology*. [Milton Park, Abingdon, U.K.] : https://doi.org/10.3109/17549507.2011.560396

Rose, T. A., Worrall, L., & McKenna, K. (2003). The effectiveness of aphasia-friendly principles for printed health education materials for people with aphasia following stroke. *Aphasiology*, *17*(10), 947–963. https://doi.org/10.1080/02687030344000319

Rosewilliam, S., Roskell, C. A., & Pandyan, A. D. (2011). A systematic review and synthesis of the quantitative and qualitative evidence behind patient-centred goal setting in stroke rehabilitation. *Clinical Rehabilitation*, *25*(6), 501–514. https://doi.org/10.1177/0269215510394467

Rosewilliam, S., Sintler, C., Pandyan, A. D., Skelton, J., & Roskell, C. A. (2016). Is the practice of goal-setting for patients in acute stroke care patient-centred and what factors influence this? A qualitative study. *CLINICAL REHABILITATION*, *30*(5), 508–519. https://doi.org/10.1177/0269215515584167

Royal College of Physicians, & Sentinel Stroke National Audit Programme (SSNAP). (2017). *Sentinel Stroke National Audit Programme (SSNAP) Clinical Audit* (Vol. 2017). Retrieved from http://www.strokeaudit.org/Guideline/Patient-Guideline.aspx42T%250Ahttp://www.strokeaudit.org/Guideline/Patient-Guideline.aspx%250Ahttps://www.nice.org.uk/guidance/qs2%250Ahttp://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Public%250

Rudd, A. G., Bowen, A., Young, G. R., & James, M. A. (2017). The latest National clinical guideline for stroke. *Clinical Medicine, Journal of the Royal College of Physicians of London*, *17*(2), 154–155. https://doi.org/10.7861/clinmedicine.17-2-154

Salter, J., Camp, Y., Pierce, L. L., & Mion, L. C. (1991). Rehabilitation nursing approaches to cerebrovascular accident: A comparison of two approaches. *Rehabilitation Nursing*, *16*(2), 62–66.

Sanders, P. (2010). *First steps in practitioner research : a guide to understanding and doing research in counselling and health and social care*. (P. Wilkins, Ed.). Ross-on-Wye: Ross-on-Wye : PCCS, 2010.

Santos Jr, H. P. O., Black, A. M., & Sandelowski, M. (2015). Timing of translation in cross-language qualitative research. *Qualitative Health Research*, *25*(1), 134–144.

Saposnik, G., & Black, S. (2009). Stroke in the very elderly: hospital care, case fatality and disposition. *Cerebrovascular Diseases*, *27*(6), 537–543.

Saposnik, G., Cote, R., Phillips, S., Gubitz, G., Bayer, N., & Minuk, J. (2008). Stroke Outcome in Those Over 80.

Sarno, M. T. (1998). *Acquired aphasia* (3rd ed.). San Diego ; London: Academic.

Saudi General Authority for Statistics. (2019). Population by Age Groups , and Gender, 1.

Saudi General Authority for Statistics. (2018). Statistical yearbook. https://www.stats.gov.sa/en/1006

Schoeb, V., Staffoni, L., Parry, R., & Pilnick, A. (2014). "what do you expect from physiotherapy?": A detailed analysis of goal setting in physiotherapy. *Disability and Rehabilitation*, *36*(20), 1679–1686. https://doi.org/10.3109/09638288.2013.867369

Schulman-Green, D. J., Naik, A. D., Bradley, E. H., McCorkle, R., & Bogardus, S. T. (2006). Goal setting as a shared decision making strategy among clinicians and their older patients. *Patient Education and Counseling*, *63*(1–2), 145–151. https://doi.org/10.1016/j.pec.2005.09.010

Schut, H. A., & Stam, H. J. (1994). Goals in rehabilitation teamwork. *Disability and Rehabilitation*, *16*(4), 223–226.

Scobbie, L, McLean, D., Dixon, D., Duncan, E., & Wyke, S. (2013). Implementing a framework for goal setting in community based stroke rehabilitation: A process evaluation. *BMC Health Services Research*, *13*(1). https://doi.org/10.1186/1472-6963-13-190

Scobbie, L., Dixon, D., & Wyke, S. (2011). Goal setting and action planning in the rehabilitation setting: Development of a theoretically informed practice framework. *Clinical Rehabilitation*, *25*(5), 468–482. https://doi.org/10.1177/0269215510389198

Scobbie, L., Wyke, S., & Dixon, D. (2009). Identifying and applying psychological theory to setting and achieving rehabilitation goals. *Clinical Rehabilitation*, *23*(4), 321–333.

Seale, C. (2004). *Qualitative Research Practice [electronic resource].* (G. Gobo, J. F. Gubrium, & D. Silverman, Eds.). London: London : SAGE Publications, 2004.

Sendiony, M. F. M. EL. (1981). *The Effect Of Islamic Sharia On Behavioural Disturbances In The Kingdom. Makka Printing and Publishing, Makkah, Saudi Arabia.*

Shankar, J. (2003). Patients' memory for medical information [3]. *Journal of the Royal Society of Medicine, 96*(10), 520. https://doi.org/10.1258/jrsm.96.10.520

Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*, *22*(2), 63–75.

Sherratt, S, Worrall, L., Pearson, C., Howe, T., Hersh, D., & Davidson, B. (2011). "Well it has to be language-related": Speech-language pathologists' goals for people with aphasia and their families. *International Journal of Speech-Language Pathology*, *13*(4), 317–328. https://doi.org/10.3109/17549507.2011.584632

Shearman & Sterling LLP. (2016). Healthcare in the Kingdom of Saudi Arabia — An Overview Sector Profile, (September). Retrieved from https://www.ic.gov.sa/media/1253/report-1-healthcare-in-the-kingdom-of-saudi-arabia-an-overview.pdf

Shrubsole, K., Worrall, L., Power, E., & O'Connor, D. A. (2016). Recommendations for post-stroke aphasia rehabilitation: an updated systematic review and evaluation of clinical practice guidelines. *Aphasiology*, 1–24. https://doi.org/10.1080/02687038.2016.1143083

Silverman, D. (2011). *Interpreting qualitative data : a guide to the principles of qualitative research* (4th ed.). London: London : SAGE, 2011.

Silverman, D. (2013). *Doing qualitative research* (Fourth edi).

Simeone, S., Savini, S., Cohen, M. Z., Alvaro, R., & Vellone, E. (2015). The experience of stroke survivors three months after being discharged home: A phenomenological investigation. *European Journal of Cardiovascular Nursing*, *14*(2), 162–169. https://doi.org/10.1177/1474515114522886

Simmons-Mackie, N. (2004). Cautiously embracing the ICF. *International Journal of Speech-Language Pathology*, *6*(1), 67–70. https://doi.org/10.1080/14417040410001669499

Simmons-Mackie, N., & Kagan, A. (1999). Communication strategies used by “good” versus “poor” speaking partners of individuals with aphasia. *Aphasiology*, *13*(9–11), 807–820. https://doi.org/10.1080/026870399401894

Simmons-Mackie, N., & Kagan, A. (2007). Application of the ICF in aphasia. *Seminars in Speech and Language.*, *28*(4), 244–253. https://doi.org/10.1055/s-2007-986521

Simmons-Mackie, N., & Lynch, K. E. (2013). Qualitative research in aphasia: A review of the literature. *Aphasiology*. [London] : https://doi.org/10.1080/02687038.2013.818098

Simmons-Mackie, N., Raymer, A., & Cherney, L. R. (2016). Communication Partner Training in Aphasia: An Updated Systematic Review. *Archives of Physical Medicine and Rehabilitation*, *97*(12), 2202-2221.e8. https://doi.org/10.1016/j.apmr.2016.03.023

Simmons-Mackie, N., Worrall, L., Murray, L. L., Enderby, P., Rose, M. L., Paek, E. J., & Klippi, A. (2016). The top ten: best practice recommendations for aphasia. *Aphasiology*, 1–21. https://doi.org/10.1080/02687038.2016.1180662

Simmons-Mackie, N., Kagan, A., O’Neill Christie, C., Huijbregts, M., McEwen, S., & Willems, J. (2007). Communicative access and decision making for people with aphasia: Implementing sustainable healthcare systems change. *Aphasiology*. [London] : https://doi.org/10.1080/02687030600798287

Simpson, G., Foster, M., Kuipers, P., Kendall, M., & Hanna, J. (2005). An organizational perspective on goal setting in community-based brain injury rehabilitation. *Disability and Rehabilitation*, *27*(15), 901–910. https://doi.org/10.1080/09638280500030589

Siyambalapitiya, S., Worrall, L., & Tomkins, B. (2013). What do people with aphasia think about their health care? Factors influencing satisfaction and dissatisfaction. *Aphasiology*. [London] : https://doi.org/10.1080/02687038.2013.811211

Skeat, J., & Perry, A. (2008). Grounded theory as a method for research in speech and language therapy. *International Journal of Language and Communication Disorders*, *43*(2), 95–109. https://doi.org/10.1080/13682820701437245

Smith, J., & Firth, J. (2011). Qualitative data analysis: the framework approach. *Nurse Researcher*, *18*(2), 52–62.

Smith, J. K. (1983). Quantitative versus qualitative research: An attempt to clarify the issue. *Educational Researcher*, *12*(3), 6–13.

Spencer, S. (2010) Language and Socioeconomic Inequality in Adolescence: Assessments and Interviews (Doctoral thesis).

Strauss, A., & Corbin, J. (1997). *Grounded theory in practice*. Thousand Oaks: Sage Publications.

Strauss, A. L. (1987). *Qualitative analysis for social scientists*. Cambridge: Cambridge University Press.

Strauss, A. L. (1990). *Basics of qualitative research : grounded theory procedures and techniques*. Newbury Park,(Calif.) ; London: Sage.

Strauss, A. L. (1998). *Basics of qualitative research : techniques and procedures for developing grounded theory* (2nd ed.). Thousand Oaks, Calif.: Sage.

Stroke Association. (2018). State of the Nation Stroke statistics, *56*(1), 198–199. https://doi.org/10.2307/2615809

Stroke Foundation. (2010). New Zealand Clinical Guidelines for stroke management. *Stroke Foundation*.

Stroke Foundation. (2017). (Australian) Clinical Guidelines for Stroke Management 2017. Chapter 5 of 8: Rehabilitation, 1–249. Retrieved from www.informme.org.au

Sugavanam, T., Mead, G., Bulley, C., Donaghy, M., & van Wijck, F. (2013). The effects and experiences of goal setting in stroke rehabilitation -- a systematic review. *Disability and Rehabilitation*, *35*(3), 177–190. https://doi.org/http://dx.doi.org/10.3109/09638288.2012.690501

Sultan Bin Abdulaziz Humanitarian City. (2019). Retrieved 10 April 2020 from https://sbahc.org.sa/en-us/AboutUs/Pages/About-us.aspx

Sumathipala, K., Radcliffe, E., Sadler, E., Wolfe, C. D. A., & McKevitt, C. (2012). Identifying the long-term needs of stroke survivors using the International Classification of Functioning, Disability and Health. *Chronic Illness*, *8*(1), 31–44. https://doi.org/10.1177/1742395311423848

Symon, G., & Cassell, C. (2012). *Qualitative Organizational Research : Core Methods and Current Challenges*. London, UNITED KINGDOM: SAGE Publications. Retrieved from http://ebookcentral.proquest.com/lib/sheffield/detail.action?docID=880788

Temple, B., & Young, A. (2004). Qualitative research and translation dilemmas. *Qualitative Research*, *4*(2), 161–178.

Thomas, C. M., Allison, R., & Latour, J. M. (2018). Using blogs to explore the lived-experience of life after stroke: “A journey of discovery I never wanted to take.” *Journal of Advanced Nursing*, *74*(3), 579–590. https://doi.org/10.1111/jan.13457

Thomas, D. R. (2006). A General Inductive Approach for Analyzing Qualitative Evaluation Data. *American Journal of Evaluation*, *27*(2), 237–246.

Thompson, A. G. H. (2007). The meaning of patient involvement and participation in health care consultations: A taxonomy. *Social Science & Medicine*, *64*(6), 1297–1310.

Threats, T. (2010). The ICF framework and third party disability: Application to the spouses of persons with aphasia. *Topics in Stroke Rehabilitation*, *17*(6), 451–457. https://doi.org/10.1310/tsr1706-451

Threats, T., & Worrall, L. (2004). Classifying communication disability using the ICF. *International Journal of Speech-Language Pathology*, *6*(1), 53–62. https://doi.org/10.1080/14417040410001669426

Threats, T. (2006). Towards an international framework for communication disorders: Use of the ICF. *J Commun Disord*, *39*(4), 251–265. https://doi.org/10.1016/j.jcomdis.2006.02.002

Threats, T. (2008). Use of the ICF for clinical practice in speech-language pathology. *International Journal of Speech-Language Pathology*, *10*(1–2), 50–60. https://doi.org/10.1080/14417040701768693

Tolman, E. C. (1932). *Purposive behavior in animals and men.* New York: Century Co.

Torregosa, M. B., Sada, R., & Perez, I. (2018). Dealing with stroke: Perspectives from stroke survivors and stroke caregivers from an underserved Hispanic community. *Nursing and Health Sciences*, *20*(3), 361–369. https://doi.org/10.1111/nhs.12414

Tregea, S., & Brown, K. (2013). What makes a successful peer-led aphasia support group? *Aphasiology*, *27*(5), 581–598. https://doi.org/10.1080/02687038.2013.796506

Tremblay, V., Croteau, C., Le Dorze, G., & Tremblay, V. (2009). A qualitative longitudinal case study of a daughter's adaptation process to her father's aphasia and stroke. *Aphasiology*. [London] : https://doi.org/10.1080/02687030801890909

Truelsen, T., & Krarup, L. H. (2010). Stroke awareness in Denmark. *Neuroepidemiology*, *35*(3), 165–170. https://doi.org/10.1159/000314344

Tuckett, A. G. (2004). Qualitative research sampling: the very real complexities. *Nurse Researcher*, *12*(1), 47–61. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=med5&NEWS=N&AN=15493214

Turner-Stokes, L., Rose, H., Ashford, S., & Singer, B. (2015). Patient engagement and satisfaction with goal planning: Impact on outcome from rehabilitation. *International Journal of Therapy and Rehabilitation*, *22*(5). https://doi.org/10.12968/ijtr.2015.22.5.210

Turner, S., & Whitworth, A. (2006). Conversational partner training programmes in aphasia: A review of key themes and participants' roles. *Aphasiology*, *20*(6), 483–510. https://doi.org/10.1080/02687030600589991

Van De Weyer, R. C., Ballinger, C., & Playford, E. D. (2010). Goal setting in neurological rehabilitation: Staff perspectives. *Disability and Rehabilitation*, *32*(17), 1419–1427. https://doi.org/10.3109/09638280903574345 van Teijlingen, E., & Hundley, V. (2001). The Importance of Pilot Studies. *Social Research Update*, (35). Retrieved from http://search.proquest.com/docview/60432019/

Visser-Meily, J. M. A., Post, M. W. M., Riphagen, I. I., & Lindeman, E. (2004). Measures used to assess burden among caregivers of stroke patients: A review. *Clinical Rehabilitation*, *18*(6), 601–623. https://doi.org/10.1191/0269215504cr776oa

Vogel, F. E. (2012). Shari'a in the politics of Saudi Arabia. *Review of Faith and International Affairs*, *10*(4), 18–27. https://doi.org/10.1080/15570274.2012.739892

Wade, D. T. (1999). Goal planning in stroke rehabilitation: Why? *Topics in Stroke Rehabilitation*, *6*(2), 1–7. https://doi.org/10.1310/MTQV-NCRV-50T0-R5T3

Wade, D. T. (2009). Goal setting in rehabilitation: an overview of what, why and how. *Clinical Rehabilitation*, *23*(4), 291–295. https://doi.org/10.1177/0269215509103551

Wade, J., Mortley, J., & Enderby, P. (2003). Talk about IT: Views of people with aphasia and their partners on receiving remotely monitored computer-based word finding therapy. *Aphasiology*, *17*(11), 1031–1056. https://doi.org/10.1080/02687030344000373

Wallace, S. J., Worrall, L., Rose, T., & Le Dorze, G. (2017). Which treatment outcomes are most important to aphasia clinicians and managers? An international e-Delphi consensus study. *Aphasiology*, *31*(6), 643–673. https://doi.org/10.1080/02687038.2016.1186265

Wallace, S. J., Worrall, L., Rose, T., Le Dorze, G., Cruice, M., Isaksen, J., Gauvreau, C. A. (2016). Which outcomes are most important to people with aphasia and their families? an international nominal group technique study framed within the ICF. *Disability and Rehabilitation*, 1–16.

World Health Organization. (2013). Country Cooperation Strategy for WHO and Saudi Arabia 2012–2016. *World Health Organization Regional Office for the Eastern Mediterranean Cairo*, 1–28. Retrieved from http://www.who.int/countryfocus/cooperation_strategy/ccs_sau_en.pdf

World Health Organization. (2001). International Classification of Functioning, Disability and Health. Geneva

Williams, J. G., Kingham, M. J., Morgan, J. M., & Davies, A. B. (1990). Retrospective review of hospital patient records. *British Medical Journal, 300*(6730). Retrieved from http://bmj.com/content/300/6730/991.full.pdf

Williams, S. E., & Freer, C. A. (1986). Aphasia: Its effect on marital relationships. *Archives of Physical Medicine and Rehabilitation*, *67*(4), 250–252. https://doi.org/10.5555/uri:pii:0003999386903801

Willis, J. (2007). Foundations of Qualitative Research: Interpretive and Critical Approaches. Thousand Oaks, California: SAGE Publications, Inc. https://doi.org/10.4135/9781452230108

Wilshire, C. E., Lukkien, C. C., & Burmester, B. R. (2014). The sentence production test for aphasia. *Aphasiology, 28*(6), 658–691.

Winkler, M., Bedford, V., Northcott, S., & Hilari, K. (2014). Aphasia blog talk: How does stroke and aphasia affect the carer and their relationship with the person with aphasia? *Aphasiology*, *28*(11), 1301–1319. https://doi.org/10.1080/02687038.2014.928665

Wood, J. P., Connelly, D. M., & Maly, M. R. (2010). “Getting back to real living”: A qualitative study of the process of community reintegration after stroke. *Clinical Rehabilitation*, *24*(11), 1045–1056. https://doi.org/10.1177/0269215510375901

Worrall, L ., & Hickson, L. (2008). The use of the ICF in speech-language pathology research: Towards a research agenda. *International Journal of Speech-Language Pathology*, *10*(1–2), 72–77. https://doi.org/10.1080/17549500701852148

Worrall, L., Sherratt, S., Rogers, P., Howe, T., Hersh, D., Ferguson, A., & Davidson, B. (2011). What people with aphasia want: Their goals according to the ICF. *Aphasiology*, *25*(3), 309–322. https://doi.org/10.1080/02687038.2010.508530

Worrall, L. (2006). Professonalism and Functional Outcomes. *Journal of Communication Disorders*, *39*(4), 320–327. Retrieved from https://search.proquest.com/docview/85631721?accountid=13828

Worrall, L., Brown, K., Cruice, M., Davidson, B., Hersh, D., Howe, T., & Sherratt, S. (2010). The evidence for a life-coaching approach to aphasia. *Aphasiology*, *24*(4), 497–514.

https://doi.org/10.1080/02687030802698152

Worrall, L., McCooey, R., Davidson, B., Larkins, B., & Hickson, L. (2002). The validity of functional assessments of communication and the Activity/Participation components of the ICIDH-2: Do they reflect what really happens in real-life? *Journal of Communication Disorders*, *35*(2), 107–137. https://doi.org/10.1016/S0021-9924(02)00060-6

Wressle, E. W. A., Öberg, B., Henriksson, C., Oberg, B., & Henriksson, C. (1999). The rehabilitation process for the geriatric stroke patient - An exploratory study of goal setting and interventions. *Disability and Rehabilitation*, *21*(2), 80–87. https://doi.org/10.1080/096382899298016

Yamey, G., & Greenwood, R. (2004). Religious views of the “medical” rehabilitation model: A pilot qualitative study. *Disability and Rehabilitation*, *26*(8), 455–462. https://doi.org/10.1080/09638280410001663021

Yaqub, B. A., Shamena, A. R., Kolawole, T. M., & Patel, P. J. (1991). Cerebrovascular disease in Saudi Arabia. *Stroke*, *22*(9), 1173–1176.

Young, C A, Manmathan, G. P., & Ward, J. C. R. (2008). Perceptions of goal setting in a neurological rehabilitation unit: A qualitative study of patients, carers and staff. *Journal of Rehabilitation Medicine*, *40*(3), 190–194. https://doi.org/10.2340/16501977-0147

Young, Carolyn A., Manmathan, G. P., & Ward, J. C. R. (2008). Perceptions of goal setting in a neurological rehabilitation unit: A qualitative study of patients, carers and staff. *Journal of Rehabilitation Medicine*, *40*(3), 190–194. https://doi.org/10.2340/16501977-0147

Appendices

Appendix A: Table of studies included in the systematic review

Study	Setting	Aim	Participant	Design and methods
1. Al-Haidary, H., Qannam, H., & Lam, T. (2015)	-King Fahd Medical City Rehabilitation Hospital. -Saudi Arabia.	Describing the development of a goal menu for patients undergoing neurological.	130 participants with neurological injury including spinal cord dysfunction, stroke, and brain injury.	Phase 1: Instrument development which included semi-structured interviews and focus groups. Phase 2: Goal menu implementation which included ranking rehabilitation goal domains.
2. Baird, T., Tempest, S., & Warland, A. (2010)	-Inpatient neurological rehabilitation setting. -UK.	Exploring the perception and experience of goal-setting theory and practice with service users.	Six service users.	Qualitative preliminary study using semi-structured interviews. Data was analysed thematically.
3. Berg, K., Askim, T., Balandin, S., Armstrong, E., & Rise, M. B. (2017)	-Hospital inpatient/outpatient rehabilitation. -Norway.	Exploring how people with aphasia experienced participation during the process of goal-setting and clinical decision making in language rehabilitation.	15 individuals with post-stroke aphasia.	Qualitative study using semi-structured in-depth interviews. Data was analysed using Systematic Text Condensation method.
4. Conneeley, A. L. (2004)	-Neurological rehabilitation hospital. -UK	Exploring the use of interdisciplinary collaborative goal planning from the perspective of patients, their relatives and professional staff.	18 participants who received neurological rehabilitation services, their significant other, and 21 medical and nursing staff.	Qualitative phenomenological study using semi-structured interviews. Data was analyzed using thematic analysis.
5. Hersh, D., Sherratt, S., Howe, T., Worrall, L., Davidson, B., & Ferguson, A. (2012)	-Acute and rehabilitation inpatient/outpatient, community, and domiciliary services. -Australia.	Exploring how speech pathologists conceptualise the nature of the "goal" in aphasia rehabilitation.	34 speech pathologists.	Qualitative study using semi-structured in-depth interviews. Data was analysed thematically.
6. Holliday, R. C., Ballinger, C., & Playford, E. D. (2007)	-Neurological rehabilitation unit -UK.	Exploring how in-patients with neurological conditions experienced two different approaches of goal-setting.	28 participants with a variety of neurological conditions.	Qualitative study using six focus groups; three for participants experiencing usual participation and three for those with increased involvement in goal-setting. Data was analysed thematically.

7. Howe, T., Davidson, B., Worrall, L., Hersh, D., Ferguson, A., Sherratt, S., & Gilbert, J. (2012)	-Aphasia rehabilitation setting. -Australia.	Identifying the rehabilitation goals that family members of people with aphasia have for themselves.	48 family members of adults with post-stroke aphasia.	Qualitative study using in-depth semi-structured interviews. Data was analysed using content analysis.
8. Kuipers, P., Carlson, G., Bailey, S., & Sharma, A. (2004)	-Community-based rehabilitation for individuals with acquired brain injury. -Australia.	Exploring issues that influence goal-setting in community rehabilitation settings.	six experienced rehabilitation coordinators.	Qualitative study using interviews. Data was analysed thematically.
9. Laver, K., Halbert, J., Stewart, M., & Crotty, M. (2010)	-Hospital based stroke unit. -Australia.	Describing the participants' readiness and ability to set goals over time.	15 stroke survivors.	Qualitative study using using a semi-structured interview at three time points: on the acute stroke unit, while participating in a subacute rehabilitation program, and 6 months after the stroke. Data was analysed using content analysis.
10. Lawler, J., Dowswell, G., Hearn, J., Forster, A., & Young, J. (1999)	-Hospital based stroke unit. -UK.	Exploring the role of goal-setting in late stroke recovery.	30 stroke survivors, 15 caregivers using, and 5 specialist nurses.	Qualitative grounded theory study design using interviews and nurses' records. `
11. Levack, W. M. M., Siegert, R. J., Dean, S. G., & McPherson, K. M. (2009)	- Neurological rehabilitation setting. -New Zealand.	Exploring how clinicians talk about the involvement of families in goal-planning during rehabilitation of adults with acquired brain injury.	Nine clinicians.	Qualitative grounded theory study design using interviews.
12. Maitra, K. K., & Erway, F. (2006)	-Rehabilitation/geriatric health care facilities. -USA.	Comparing the perceptions of clients and occupational therapists regarding their involvement in the process of client-centered approach.	11 occupational therapists and 30 clients.	Qualitative study using semi-structured interviews. Descriptive statistics were used to analyse the item data.
13. Parsons, J. G. M., Plant, S. E., Slark, J., & Tyson, S. F. (2016)	-Stroke rehabilitation settings. -UK.	Exploring clinician's perceptions of the patient as an active partner in setting goals and factors that impact patient involvement.	20 stroke rehabilitation clinicians	Qualitative study using semi-structured interviews. Data was analysed using a general inductive analysis approach.
14. Power, E., Anderson, A., & Togher, L. (2011)	- Neurological rehabilitation. -Australia.	Describing the application of the World Health Organization's International Classification of Functioning,	37-year-old man and his mother.	Qualitative interviews and quantitative communication assessments methods were used.

		Disability and Health (ICF) to communication assessment and goal-setting to a person with Huntington's Disease		
15. Rohde, A., Townley-O’Neill, K., Trendall, K., Worrall, L., & Cornwell, P. (2012)	-Inpatient/outpatient rehabilitation unit in a metropolitan hospital. -Australia.	Identifying the similarities and differences between PWA’s goals and therapist goals in rehabilitation to explore reasons why any differences occur.	Three speech-language pathologists and four PWA.	Qualitative study using in-depth semi-structured interviews. Data was analysed using content analysis.
16. Rosewilliam, S., Sintler, C., Pandyan, A. D., Skelton, J., & Roskell, C. A. (2016)	-Acute stroke unit in a large teaching hospital. -UK.	Exploring whether goal-setting for rehabilitation with acute stroke survivors is patient- centred and identifying factors which influence the adoption of patient-centredness in goal-setting practice.	Seven stroke survivors and seven health-care professionals.	Multiple qualitative methods were used. Semi-structured interviews were conducted, and data from patients’ records and observation of team meetings were recorded. Data was analysed using qualitative methods to identify themes.
17. Schulman-Green, D. J., Naik, A. D., Bradley, E. H., McCorkle, R., & Bogardus, S. T. (2006)	-Three residential sites: a high-income independent living facility (one group), a subsidized assisted living facility (two groups), and a private condominium complex (one group). -USA	Exploring how older adults consider and discuss their life and health goals during the clinical encounter.	Community-dwelling older persons (n = 42), geriatricians and internists (n = 6), and rehabilitation nurses (n = 5).	Qualitative study using six focus groups. Group interactions were tape-recorded, transcribed, and analysed using content analysis.
18. Sherratt, S., Worrall, L., Pearson, C., Howe, T., Hersh, D., & Davidson, B. (2011)	-Three rehabilitation sites. -Australia.	Examining the goals that clinicians set for their clients with aphasia and their family members.	34 speech-language pathologists.	Qualitative study using in-depth interviews. Data was analysed using content analysis.
19. Worrall, L., Sherratt, S., Rogers, P., Howe, T., Hersh, D., Ferguson, A., & Davidson, B. (2011)	-Three rehabilitation sites. -Australia.	Describing PWA’s goals in rehabilitation.	50 participants with post-stroke aphasia	Qualitative study using in-depth interviews. Goals were coded using the World Health Organization’s International Classification of Functioning, Disability and Health (ICF) framework.

Appendix B: Quality evaluation of included studies in the systematic review using CASP (2017) checklist

Studies Checklist	(Al-Haidary et al., 2015)	(Baird, Tempest, & Warland, 2010)	(Berg et al., 2017)	Conneeley, A. L. (2004)	(Hersh et al., 2012)	(Holliday et al., 2007)	(Howe et al., 2012)	(Kuipers, Carlson, Bailey, & Sharma, 2004)	(Laver et al., 2010)	(Lawler et al., 1999)	(Levack et al., 2009)	(Maitra & Erway, 2006)	(Parsons, Plant, Slark, & Tyson, 2016)	(Power et al., 2011)	(Rohde et al., 2012)	(Rosewilliam et al., 2016)	(Schulman-Green et al., 2006)	(Sherratt et al., 2011)	(Worrall et al., 2011)
1. Was there a clear statement of the aims of the research?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
2. Is a qualitative methodology appropriate?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
3. Was the research design appropriate to address the aims of the research?	Y Not clear how interview questions were developed	Y Not clear how interview questions were developed	Y Not clear how interview questions were developed	Y Not clear how interview questions were developed	Y Not clear how interview questions were developed	Y Questions were based on literature findings	Y Not clear how interview questions were developed	Y Interview questions were developed after a literature review and input from experts	Y Interview questions were developed after a literature review and input from experts	Y Not clear how interview questions were developed	Y Not clear how interview questions were developed	Y Interview questions were adopted	Y Questions informed by previous studies	Y Questions were designed according to ICF framework	Y Not clear how interview questions were developed	Y Questions were adopted from a previous study	Y Not clear how interview questions were developed	Y Not clear how interview questions were developed	Y Not clear how interview questions were developed
4. Was the recruitment strategy appropriate to the aims of the research?	N Recruitment was not clearly reported	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y Case study	Y	Y	Y	Y	Y
5. Was the data collected in a way that addressed the	Y Setting was not justified and	Y Setting was not justified	Y	Y Saturation was not discussed	Y Saturation was not discussed	Y Saturation was not discussed	Y Setting was not justified	Y Setting was not justified	Y Setting was not justified	Y Setting was not justified	Y	Y Setting was not justified	Y	Y	Y Setting was not justified	Y	Y Setting was not justified	Y Setting was not justified	Y Setting was not justified

research issue?	saturation was not discussed	and saturation was not discussed					and saturation was not discussed	and saturation was not discussed		and saturation was not discussed		and saturation was not discussed			and saturation was not discussed		and saturation was not discussed	and saturation was not discussed	and saturation was not discussed
6. Has the relationship between researcher and participants been adequately considered?	N Not clear if this was considered	N Not clear if this was considered	Y	Y	N Not clear if this was considered	N Not clear if this was considered	N Not clear if this was considered	N Not clear if this was considered	N Not clear if this was considered	N Not clear if this was considered	N Not clear if this was considered	N Not clear if this was considered	N Not clear if this was considered	N Not clear if this was considered	N Not clear if this was considered	Y	N Not clear if this was considered	Y	N Not clear if this was considered
7. Have ethical issues been taken into consideration?	Y	Y	Y	Y	Y	Y	Y	Y	Y	N Ethics was not reported	Y	Y	Y	Y	Y	Y	Y	Y	Y
8. Was the data analysis sufficiently rigorous?	Y	CT analysis was not reported in detail	Y	CT analysis was not reported in detail	Y	Y	Y	Y	Y	CT analysis was not reported in detail	Y	Y	Y	Y	Y	Y	CT analysis was not reported in detail	Y	Y
9. Is there a clear statement of findings?	Y	Y Credibility was not reported in detail	Y Credibility was not reported	Y Credibility was not reported	Y	Y	Y	Y	Y	Y Credibility was not reported	Y	Y	Y Credibility was not reported in detail	Y	Y Credibility was not reported in detail	Y	Y Credibility was not reported	Y	Y
10. How valuable is the research?	Y	Y	Y	Y	Y Limitations were not reported	Y	Y	Y	Y	Y Limitations were not reported	Y	Y	Y	Y	Y	Y	Y	Y	Y

Y=Yes
N=No
CT=Can’t tell

Appendix C: Filled form of an included study in the Systematic review

Extraction item	Details
Study	Berg, K., Askim, T., Balandin, S., Armstrong, E., & Rise, M. B. (2017). Experiences of participation in goal setting for people with stroke-induced aphasia in Norway. A qualitative study. *Disability and Rehabilitation*, *39*(11), 1122–1130.
Setting and country	-Hospital inpatient/outpatient rehabilitation. -Norway.
Aim	Exploring how people with aphasia experienced participation during the process of goal-setting and clinical decision making in language rehabilitation.
Participants	15 individuals with post-stroke aphasia.
Design and data collection methods	Qualitative study design using semi-structured in-depth interviews.
Interview questions or topics	1. Do you remember what your expectations were when you met with a speech pathologist for the first time? 2. What's important to you now in speech pathology? 3. What are you doing in speech pathology now? What are you targeting? 4. How are decisions on what to do in therapy made? 5. Do you have common goals with your speech pathologist? 6. Is there anything else you would have liked to target? 7. How will you describe the interaction between you and your speech pathologist? 8. When I say client participation, what does it mean to you?
Analysis methods	Data was analysed using a Systematic Text Condensation method. The analysis method is based on Georgi's phenomenological analysis. The Systematic Text Condensation method contains four steps to analyse qualitative data.

Findings and key themes	Theme 1. Pleased with services. The overall impression was that the participants with stroke-induced aphasia were pleased with the services delivered by the speech pathologists. This was despite the fact that the participants struggled to articulate common goals between themselves and the speech pathologists and what they were doing during the therapy sessions. Theme 2. Vagueness in language rehabilitation (vagueness in collaborative goal setting, vague content of therapy, vague timeframe of therapy). The majority of the participants described the content and time frames of therapy as being somewhat unclear. Theme 3. Personal goals exist. Most of the people with stroke-induced aphasia in this study were able to express their own goals for rehabilitation. These goals could be grouped as language goals and life goals. Language goals: The specific language goals for some of the participants were closely connected to what was done in language rehabilitation Life goals: The characteristic of these goals was that the participants had not discussed them with their speech pathologist or their personal goals had not been incorporated into the language rehabilitation. However, none of the participants with these goals expressed any dissatisfaction with this situation. Theme 4. Desired level of participation: The participants in this study were divided into two groups regarding their wish for collaboration with their speech pathologist, those who wanted to participate in goal setting and treatment planning and those who wanted to trust the expert. A majority of the participants expressed that they trusted suggestions given and decisions made by the speech pathologists
Quality of the study	The study was evaluated using CASP (2017) checklist. Please refer to Appendix B

Appendix D: Codes of studies included in the systematic review

Participant group	Studies	Codes and sub-codes assigned for interview questions or topics	Codes and sub-codes assigned for study outcomes
Individuals with medical conditions	15. Rohde, A., Townley-O'Neill, K., Trendall, K., Worrall, L., & Cornwell, P. (2012). 14. Power, E., Anderson, A., & Togher, L. (2011). 1. Al-Haidary, H., Qannam, H., & Lam, T. (2015). 6. Holliday, R. C., Ballinger, C., & Playford, E. D. (2007). 16. Rosewilliam, S., Sintler, C., Pandyan, A. D., Skelton, J., & Roskell, C. A. (2016). 9. Laver, K., Halbert, J., Stewart, M., & Crotty, M. (2010). 2. Baird, T., Tempest, S., & Warland, A. (2010).	**Experience with condition** • Patient's experience with the medical condition. • The impact of the medical condition. **Experience with services** • Patient's experience with previous therapy. **Current therapeutic goals** • Therapeutic goals of current therapy. **Desired goals** • Patient's desired goals at an early stage. • Patient's desired goals at present. • Daily activities prior to the medical condition. • What goals mean to the patient. **Satisfaction** • Patient's view on the efficacy of therapy. **Progress** • Factors helping in further recovery. • Effect on motivation. **Communication skills** • Communication skills of the patient. • Barriers and facilitators of better communication. **"Goal" definition** • Patient's thoughts on the word "goal".	**Experience with condition** • Disempowerment by aphasia. • Support groups provide support and help. **"Goal" definition** • Problems in understanding the concept of "goal" in early stages. **Communication skills** • Ability to express goals with the aid of supported conversation. **Current therapeutic goals** • Difficulties in reporting clear rehabilitation goals. • Recovering and regaining physical function goals. • Communicative function goals. • Independence goals. • Long-term goals viewed as "scary". • Long-term were not linked to short-term goals. **Desired goals** • Vague goals. • General or unrealistic goals. • Speech therapy that met their needs at different stages. • Communication goals (e.g. being understood or finding words). • Returning to previously performed activities (e.g. to return to work, to travel, or to drive). • Functional goals (social, leisure and work). • Education and obtaining information regarding stroke and aphasia. • Using patient-friendly terminology and materials. • Goals related to contributing to society (e.g. supporting others with aphasia).

	19. Worrall, L., Sherratt, S., Rogers, P., Howe, T., Hersh, D., Ferguson, A., & Davidson, B. (2011). 10. Lawler, J., Dowswell, G., Hearn, J., Forster, A., & Young, J. (1999). 12. Maitra, K. K., & Erway, F. (2006). 17. Schulman-Green, D. J., Naik, A. D., Bradley, E. H., McCorkle, R., & Bogardus, S. T. (2006). 3. Berg, K., Askim, T., Balandin, S., Armstrong, E., & Rise, M. B. (2017). 4. Conneeley, A. L. (2004).	• “SMART goal” term. **The involvement of others in goal-setting** • Patient’s involvement in the process of goal-setting. • People involved in the process. • Multidisciplinary team in goal-setting. • Patient’s ability and readiness to set their own goals. • Goal discussion. • Key working. **Goal-setting process** • Explanation of the goal-setting process. • Changes to improve the goal-setting process. • Feelings about previous experience of goal-setting. • Timing of goal reviews. • Information needs. **Factors influencing an effective/collaborative goal-setting** • Barriers and facilitators of goal-setting. • Positive and less positive aspects.	**Goal-setting process** • The importance of establishing an effective goal-setting process. • Past experience influenced the understanding of goals and setting them (e.g. goals in employment setting). • The importance of setting goals at a challenging level. **The involvement of others in goal-setting** • Participating in setting intervention goals was unnecessary because clinicians knew what was best. • Participant’s goals were not always discussed with clinicians. • Less collaborative approach in goal-setting. • Less participation in the acute phase after stroke. • Unable to recall specific goals discussed with therapists. • Readiness to set goals after stroke varied between individuals. **Factors influencing effective/collaborative goal-setting** • Personal perspectives. • Assumptions and response. • Prior experience. • Medical condition characteristics. • Reduced level of health literacy. • Collaboration. • Feedback from multidisciplinary team.

Family members/ caregivers	7. Howe, T., Davidson, B., Worrall, L., Hersh, D., Ferguson, A., Sherratt, S., & Gilbert, J. (2012). 14. Power, E., Anderson, A., & Togher, L. (2011). 10. Lawler, J., Dowswell, G., Hearn, J., Forster, A., & Young, J. (1999). 4. Conneeley, A. L. (2004).	**Experience with condition** • Experience of having a close relative with a medical condition. • The impact of the medical condition. **Experience with services** • Family's experience with rehabilitation and service. • The rehabilitation services they would have wanted, or want now. **Communication skills** • The communication skills of their relatives with medical conditions. • Environmental factors: barriers and facilitators of better communication. **Current therapeutic goals** • Therapeutic goals of current therapy. **Desired goals** • Family's goals and needs for themselves. • Family's goals for their relative patients. **The involvement of others in goal-setting** • Family's involvement in the process of goal-setting. • Key working. **Goal-setting process** • Timing of goal reviews. • Information needs. **Factors influencing an effective/collaborative goal-setting** • Positive and less positive aspects. **Progress** • Effect on motivation.	**Desired goals** • To be included in rehabilitation. • Maintaining a relationship with their close relative with a medical condition. • Education and information about the medical condition and prognosis. • Hope and support. • Coping with the situation, and maintaining a good physical and emotional status. • Receiving communication training to communicate better with their relatives with aphasia. • Functional goals for their relatives with medical conditions. **Patient and family involvement in rehabilitation** • A lack of involvement. • Influential factors (transportation, service setting, and clinician's decision).

Clinicians	18. Sherratt, S., Worrall, L., Pearson, C., Howe, T., Hersh, D., & Davidson, B. (2011). 15. Rohde, A., Townley-O'Neill, K., Trendall, K., Worrall, L., & Cornwell, P. (2012). 16. Rosewilliam, S., Sintler, C., Pandyan, A. D., Skelton, J., & Roskell, C. A. (2016). 5. Hersh, D., Sherratt, S., Howe, T., Worrall, L., Davidson, B., & Ferguson, A. (2012). An analysis of the "goal" in aphasia 10. Lawler, J., Dowswell, G., Hearn, J., Forster, A., & Young, J. (1999). 11. Levack, W. M. M., Siegert, R. J., Dean, S. G., & McPherson, K. M. (2009). 12. Maitra, K. K., & Erway, F. (2006).	**Experience with services** • Clinician's experience in providing intervention to patients and their families. **Current therapeutic goals** • Clinician's current therapeutic goals for patients and their families. **"Goal" definition** • Clinician's definition of "goal". **Desired goals** • Clinician's perceptions of patients' desired goals. **Patient and family involvement in rehabilitation** • The involvement level of patients and families in therapy. • The meaning of "client-centred care". • Barriers and facilitators of "client-centred care". **Goal-setting process** • The process of selecting and reviewing goals. • The influence of clinician's skills, values, and relationship with client. • Skills needed for an effective goal-setting process. • Timing of goal reviews. • Documentation. • Ease of use. **The involvement of others in goal-setting** • The purpose of including families.	**Current therapeutic goals** • Impairment-based or functional-based approaches, • Using impairment-based and functional-based approaches simultaneously. • Coping and participation goals (increasing confidence, accepting aphasia, and referral to support groups). • Education goals. • The presence of matched and mismatched goals (e.g. work and hobbies). • Mismatched because of barriers (e.g. service delivery approach, impaired communication, or goals outside the scope of clinician's practice). **Patient and family involvement in rehabilitation** • Family involvement is important. • Communication training for family members is helpful. • Educational materials and information provision. • Planning goals for families might not be within the scope of practice of clinicians in certain settings. • Family involvement provides support to them. **Goal-setting process** • Goal identification. • Identifying enabling objectives. • Goal review. • Goal achievement. • Patient's communicative needs. • Language impairment goals following formal and informal assessments. • Clinicians' awareness of their role and impact in the process of goal-setting. • Lack of goal-setting standardised procedure in rehabilitation. **The involvement of others in goal-setting**

	17. Schulman-Green, D. J., Naik, A. D., Bradley, E. H., McCorkle, R., & Bogardus, S. T. (2006). 8. Kuipers, P., Carlson, G., Bailey, S., & Sharma, A. (2004). 13. Parsons, J. G. M., Plant, S. E., Slark, J., & Tyson, S. F. (2016). 4. Conneeley, A. L. (2004).	• The involvement of patients and family members in goal-setting. • Goal negotiation and discussion. • Communication with the team. • Clarification of roles. • Key working. **Factors influencing an effective/collaborative goal-setting** • Barriers and facilitators of setting intervention goals and of involving patients and families. • Positive and less positive aspects. **Progress** • Goals to monitor patient's progress. • Clinician's views on patient's participation in setting goals in relation to a good recovery. **Satisfaction** • The effectiveness of clinician's intervention.	• Family involvement in goal planning is important. • Lack of family input. • Some patients and families had no goals. • Discussing goals varied amongst professionals and patients. • Discussing goals early is beneficial to reducing later conflicts. **Factors influencing effective/collaborative goal-setting** • Dysfunctional therapeutic relationship (e.g. rapport, communication and priorities). • Service-related factors (work environment, professional hierarchy, policies). • Patient's beliefs and attributes. • Clinician's beliefs and knowledge (e.g. clinicians might set goals based on beliefs of which patients might not have adequate knowledge). • Family members' own agenda that does not match the team's view. • Patient's characteristics (e.g. cognitive skills, or a lack of motivation). • Presumption that all patients' goals are similar. • Knowledge of the condition. • Family presence (time, transportation, and deciding not to engage.) **"Goal" definition** • Desires • SMART goals (specific, measurable, achievable, realistic, and time-bound). • Impairment or functional goal. • Steps (time or difficulty). • Contracts (allow clients to judge the efficiency of intervention). • Implicit goals. • The formality in the word "goal", and the fixed ideas when working with stroke patients.

Appendix E: First draft of interview questions based on the systematic review (piloted interview questions)

PWA interview questions	Family members interview questions	SLTs interview questions
1- Tell me about your aphasia. *Prompt: your communication.* 2- Tell me about the speech and language therapy you had before. 3- What did you want or hope when you first had aphasia? 4- What are your goals now? *Prompt: What do you want/hope/desire now?* 5- Do you work in speech and language therapy to achieve these goals? (in relation to the previous question) *Clarification probes:* *If yes, what activities do you do in therapy?* *If no, what do you do in speech and language therapy now and why?*	1- Tell me about your experience of having a close family member with stroke/aphasia. *Prompt: their communication.* 2- Tell me about the speech and language therapy your family member had before. 3- Tell me what were your goals for your family member when they first had aphasia. *Prompt: what did you want or hope for them in relation to communication?* 4- What are your goals for them now? *Prompt: what do you want/hope/desire for them now in relation to communication?* 5- Tell me what they do in speech and language therapy now.	1- Tell me about your experience in providing speech and language therapy to the person with aphasia and his/her family members (in general). 2- In your perspective, what do you think the patient's goals were? 3- In your perspective, what do you think the family member's goals were? (for them and the patient) 4- What are your therapeutic goals for your patient with aphasia? 5- What do you do in therapy to achieve these goals? 6- Do you have goals for their family members? *Clarification probes* *If yes, what are these?*

6- Who chose your goals for speech and language therapy? 7- Did you help your SLT to choose goals? *Clarification probes:* *If yes, how?* *If no, why?* 8- Do you think it is important to help your SLTs in choosing goals? *Clarification probes:* *If yes, why?* *If no, why?* 9- Do you notice any progress in your communication with therapy? *Clarification probes:* *If yes, tell me more about it.* *If no, why?* 10- What might help you for further improvement in your communication?	6- Do you have goals for yourself as a close family member to a person with aphasia? *Clarification probes* If yes, what are these goals? Tell me what you do to achieve them. 7- Tell me about your involvement in the aphasia rehabilitation of your family member. 8- How were speech and language therapy goals chosen? 9- Were you involved in the process of choosing goals? *Clarification probes* *If yes, how?* *If no, why?* 10 Do you think it is important for you as a family member to be involved in choosing goals? *Clarification probes*	*If no, why?* 7- Tell me about the involvement of the patient and his/her family in the rehabilitation process. 8- How were speech and language therapeutic goals chosen? *Prompt: what is the process of goal-setting?* 9- Tell me about the patient and his/her family involvement in the process of goal-setting. 10- In your perspective, is it important to include patients and families in the goal-setting process? *Clarification probes* *If yes, how?* *If no, why?* 11- What factors do you think facilitate or hinder the involvement? 12- In your perspective, what is a “goal”? *Prompt: how would you define a “goal”?*

	If yes, why? What factors do you think facilitate or hinder the involvement? *If no, why?* 11- Do you notice any progress in your family member's communication with therapy? *Clarification probes* *If yes, tell me more about it.* *If no, why?* 12- What do you think might help for further improvement in the communication of your family member?	

Appendix F: Last version of interview questions and rationale

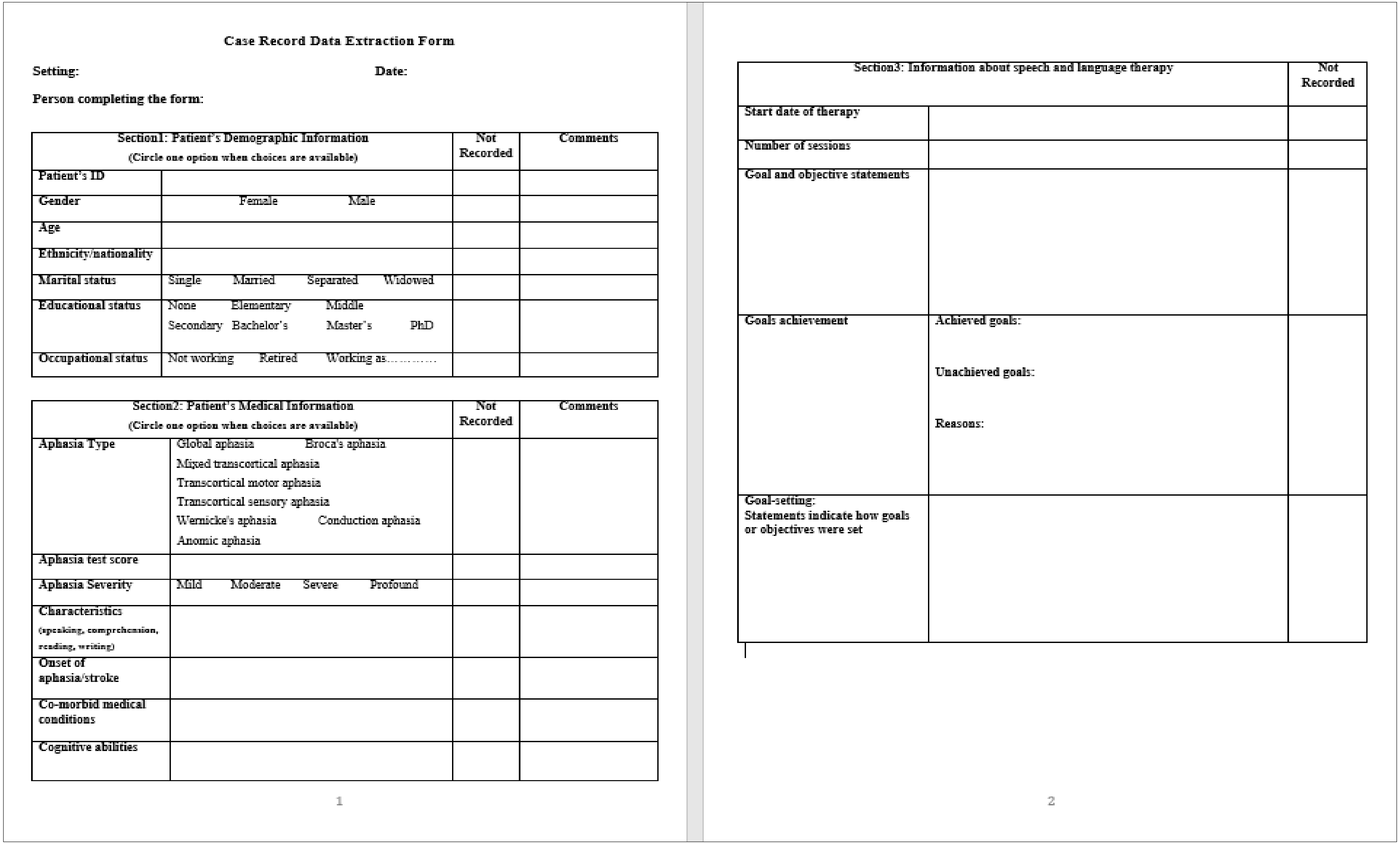
	People with aphasia	**Family members**	**SLTs**	**Rationale**
Experience with condition and impact on communication skills	-Tell me about your stroke/aphasia when you first had it. *Prompt: your communication.* -Tell me about your communication now.	-Tell me about your experience of having a close family member with stroke/aphasia. *Prompt: When it first happened/their communication.*	____________	Questions on experiencing the condition were reported in literature that investigated goals and goal-setting. Answers to these questions will provide an understanding of how PWA and families construct the experience of stroke and aphasia, the context of participant's experience, as well as how aphasia affected the communication of PWA and other aspects in their lives. SLTs were not asked about the experience, as these are specific questions to people who have lived the experience.
Experience with services	-Tell me about the speech and language therapy you had before. *Prompt: when you first had aphasia.*	-Tell me about the speech and language therapy your family member had before.	-Tell me about your experience in providing speech and language therapy to the person with aphasia and his/her family members (in general).	Questions on experience with services were reported in literature that investigated goals and goal-setting. Answering questions on the experience of speech and language therapy will prepare participants to move into the context of rehabilitation.

Desired goals	-What did you want or hope when you first had aphasia? *Prompt: what things you wanted in your communication.* -What do you want or desire now? *Prompt: in your communication.*	-Tell me what were your goals for your family member when they first had aphasia. *Prompt: what did you want or hope for them in relation to communication?* -What are your goals for them now? *Prompt: what do you want/hope/desire for them now in relation to communication?*	-In your perspective, what do you think the patient's goals were? -In your perspective, what do you think the family member's goals were? (for them and the patient)	Questions on desired goals were reported in literature that investigated goal-setting. These questions will allow understanding what PWA and their families want in aphasia therapy, and whether or not the needs and desires were targeted in therapy. Asking SLTs about their perception of PWA's and families' goals will allow knowing if SLTs consider others' input.
Current therapeutic goals	-Tell me what you do in speech and language therapy now. -Is there anything else you want to do in therapy?	-Tell me what they do in speech and language therapy now. -Do you have goals for yourself as a close family member to a person with aphasia? *Clarification probes* If yes, what are these goals? Tell me what you do to achieve them.	-What are your therapeutic goals for your patient with aphasia? -What do you do in therapy to achieve these goals? -Do you have goals for their family members? *Clarification probes* *If yes, what are these?* *If no, why?*	Questions on current therapeutic goals were reported in literature that investigated goal-setting. These questions will allow understanding whether or not the needs were targeted in therapy. Asking "Is there anything else you want to do in therapy?" will allow to understand participants' expectations in relation to their therapeutic goals.
Patients' and families'	____________	-Tell me about your involvement in the aphasia	-Tell me about the involvement of the patient and	Questions on the involvement of patients and families in therapy were

involvement in rehabilitation		rehabilitation of your family member.	his/her family in the rehabilitation process.	reported in literature that investigated goal-setting. Answering these questions will allow understanding the total approach to rehabilitation, thus understanding the context of goal-setting. PWA were not asked questions on the general involvement in therapy, as they are already part of it, and because they will be asked about their involvement in goal-setting specifically.
Goal-setting process, involvement, and influential factors	-Who chose your goals for speech and language therapy? -Did you help your SLT to choose goals? *Clarification probes* *If yes, how?* *If no, why?* -Do you think it is important to help your SLTs in choosing goals? *Clarification probes* *If yes, how?* *If no, why?*	-How were speech and language therapy goals chosen? -Were you involved in the process of choosing goals? *Clarification probes* *If yes, how?* *If no, why?* -Do you think it is important for you as a family member to be involved in choosing goals? *Clarification probes*	-How were speech and language therapeutic goals chosen? *Prompt: what is the process of goal-setting?* -Tell me about the patient and his/her family involvement in the process of goal-setting. -In your perspective, is it important to include patients and families in the goal-setting process? *Clarification probes* *If yes, how?* *If no, why?*	Questions on the process, involvement, and factors were reported in literature that investigated goal-setting. Answering these questions will highlight the process of goal-setting from three viewpoints. PWA, family members, and SLTs were asked specific questions on the participation in goal-setting. SLTs were asked about their process of goal-setting because they are healthcare providers.

		If yes, why? What factors do you think facilitate or hinder the involvement? *If no, why?*	-What factors do you think facilitate or hinder the involvement?	
Progress	-Do you notice any progress in your communication with therapy? *Clarification probes* *If yes, tell me more about it?* *If no, why?* -What might help you for further improvement in your communication?	-Do you notice any progress in your family member's communication with therapy? *Clarification probes* *If yes, tell me more about it.* *If no, why?* -What do you think might help for further improvement in the communication of your family member?	____________	Questions on skills and progress were reported in literature that investigated goal-setting. These questions will allow understanding whether PWA and their families notice progress and are satisfied with therapeutic goals. SLTs were not asked these questions, as not to indicate that their skills as therapists are being judged by the researcher.
Goal definition	____________	____________	-In your perspective, what is a "goal"? *Prompt: how would you define a "goal"?*	Questions on the definition of "goal" were reported in literature that investigated goal-setting. Answering this question will highlight how SLTs view goals that they set in aphasia therapy. This will add depth to the data of SLTs. PWA and their families were not asked to define a "goal", as this is an abstract concept.

Appendix G: Case record data extraction tool



Case Record Data Extraction Form

Setting: **Date:**

Person completing the form:

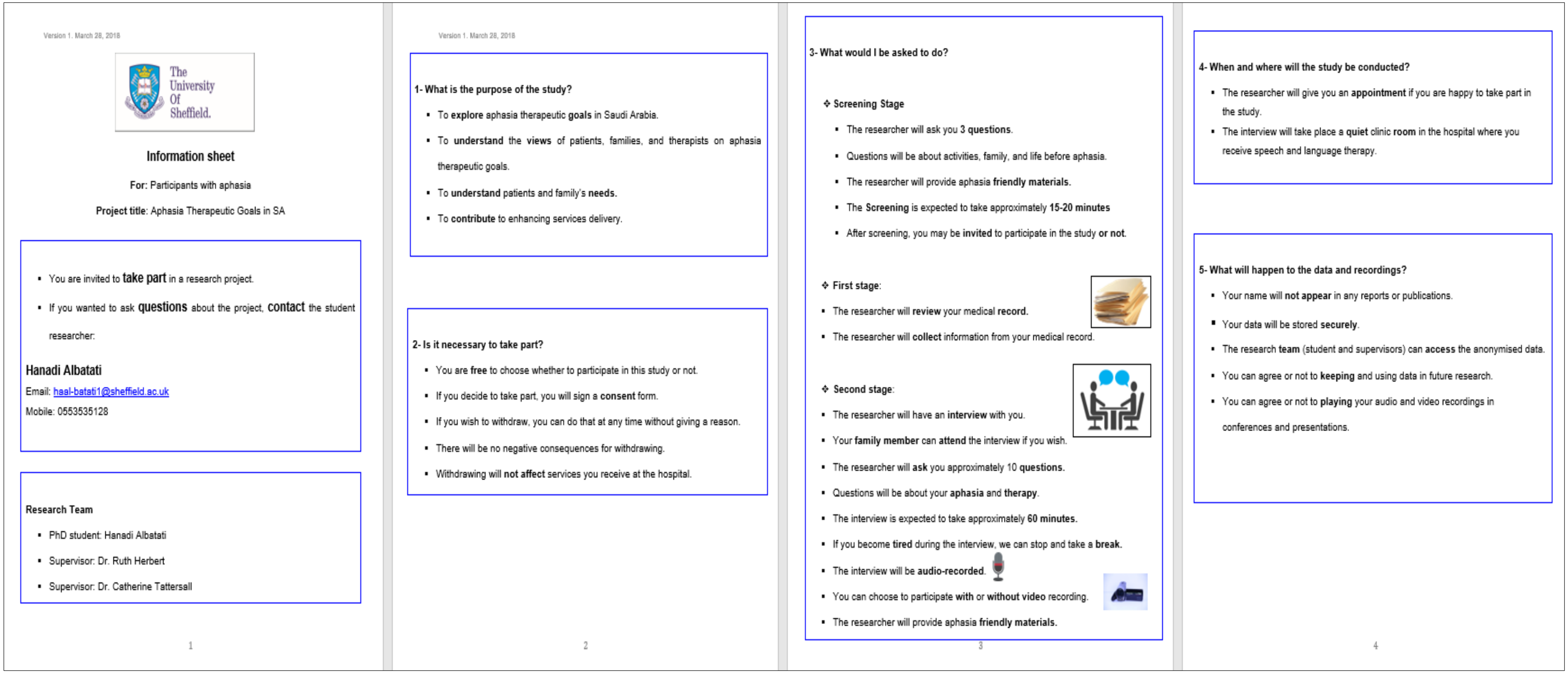
Section1: Patient's Demographic Information (Circle one option when choices are available)		Not Recorded	Comments
Patient's ID			
Gender	Female Male		
Age			
Ethnicity/nationality			
Marital status	Single Married Separated Widowed		
Educational status	None Elementary Middle Secondary Bachelor's Master's PhD		
Occupational status	Not working Retired Working as…………		

Section2: Patient's Medical Information (Circle one option when choices are available)		Not Recorded	Comments
Aphasia Type	Global aphasia Broca's aphasia Mixed transcortical aphasia Transcortical motor aphasia Transcortical sensory aphasia Wernicke's aphasia Conduction aphasia Anomic aphasia		
Aphasia test score			
Aphasia Severity	Mild Moderate Severe Profound		
Characteristics (speaking, comprehension, reading, writing)			
Onset of aphasia/stroke			
Co-morbid medical conditions			
Cognitive abilities			

Section3: Information about speech and language therapy		Not Recorded
Start date of therapy		
Number of sessions		
Goal and objective statements		
Goals achievement	**Achieved goals:** **Unachieved goals:** **Reasons:**	
Goal-setting: Statements indicate how goals or objectives were set		

Appendix H:

Aphasia-friendly information sheet



Version 1. March 28, 2018

The University Of Sheffield.

Information sheet

For: Participants with aphasia

Project title: Aphasia Therapeutic Goals in SA

- You are invited to **take part** in a research project.
- If you wanted to ask **questions** about the project, **contact** the student researcher:

Hanadi Albatati

Email: haal-batati1@sheffield.ac.uk

Mobile: 0553535128

Research Team

- PhD student: Hanadi Albatati
- Supervisor: Dr. Ruth Herbert
- Supervisor: Dr. Catherine Tattersall

Version 1. March 28, 2018

1- What is the purpose of the study?

- To **explore** aphasia therapeutic **goals** in Saudi Arabia.
- To **understand** the **views** of patients, families, and therapists on aphasia therapeutic goals.
- To **understand** patients and family's **needs.**
- To **contribute** to enhancing services delivery.

2- Is it necessary to take part?

- You are **free** to choose whether to participate in this study or not.
- If you decide to take part, you will sign a **consent** form.
- If you wish to withdraw, you can do that at any time without giving a reason.
- There will be no negative consequences for withdrawing.
- Withdrawing will **not affect** services you receive at the hospital.

3- What would I be asked to do?

❖ **Screening Stage**

- The researcher will ask you 3 **questions**.
- Questions will be about activities, family, and life before aphasia.
- The researcher will provide aphasia **friendly materials.**
- The **Screening** is expected to take approximately **15-20 minutes**
- After screening, you may be **invited** to participate in the study **or not.**

❖ **First stage**:

- The researcher will **review** your medical **record.**
- The researcher will **collect** information from your medical record.

❖ **Second stage**:

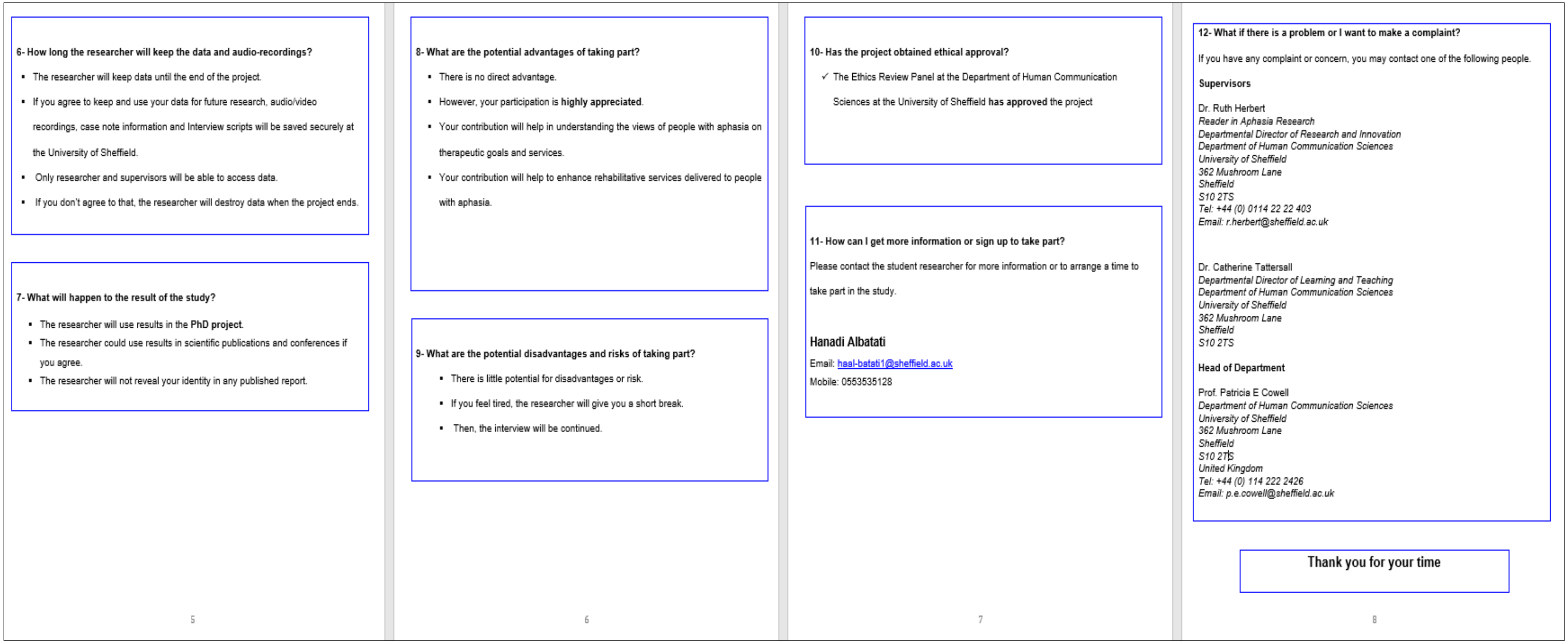
- The researcher will have an **interview** with you.
- Your **family member** can **attend** the interview if you wish.
- The researcher will **ask** you approximately 10 **questions.**
- Questions will be about your **aphasia** and **therapy**.
- The interview is expected to take approximately **60 minutes.**
- If you become **tired** during the interview, we can stop and take a **break.**
- The interview will be **audio-recorded**.
- You can choose to participate **with** or **without video** recording.
- The researcher will provide aphasia **friendly materials.**

4- When and where will the study be conducted?

- The researcher will give you an **appointment** if you are happy to take part in the study.
- The interview will take place a **quiet** clinic **room** in the hospital where you receive speech and language therapy.

5- What will happen to the data and recordings?

- Your name will **not appear** in any reports or publications.
- Your data will be stored **securely**.
- The research **team** (student and supervisors) can **access** the anonymised data.
- You can agree or not to **keeping** and using data in future research.
- You can agree or not to **playing** your audio and video recordings in conferences and presentations.



6- How long the researcher will keep the data and audio-recordings?

- The researcher will keep data until the end of the project.
- If you agree to keep and use your data for future research, audio/video recordings, case note information and Interview scripts will be saved securely at the University of Sheffield.
- Only researcher and supervisors will be able to access data.
- If you don't agree to that, the researcher will destroy data when the project ends.

7- What will happen to the result of the study?

- The researcher will use results in the PhD **project**.
- The researcher could use results in scientific publications and conferences if you agree.
- The researcher will not reveal your identity in any published report.

8- What are the potential advantages of taking part?

- There is no direct advantage.
- However, your participation is **highly appreciated**.
- Your contribution will help in understanding the views of people with aphasia on therapeutic goals and services.
- Your contribution will help to enhance rehabilitative services delivered to people with aphasia.

9- What are the potential disadvantages and risks of taking part?

- There is little potential for disadvantages or risk.
- If you feel tired, the researcher will give you a short break.
- Then, the interview will be continued.

10- Has the project obtained ethical approval?

- ✓ The Ethics Review Panel at the Department of Human Communication Sciences at the University of Sheffield **has approved** the project

11- How can I get more information or sign up to take part?

Please contact the student researcher for more information or to arrange a time to take part in the study.

Hanadi Albatati

Email: haal-batati1@sheffield.ac.uk

Mobile: 0553535128

12- What if there is a problem or I want to make a complaint?

If you have any complaint or concern, you may contact one of the following people.

Supervisors

Dr. Ruth Herbert
Reader in Aphasia Research
Departmental Director of Research and Innovation
Department of Human Communication Sciences
University of Sheffield
362 Mushroom Lane
Sheffield
S10 2TS
Tel: +44 (0) 0114 22 22 403
Email: r.herbert@sheffield.ac.uk

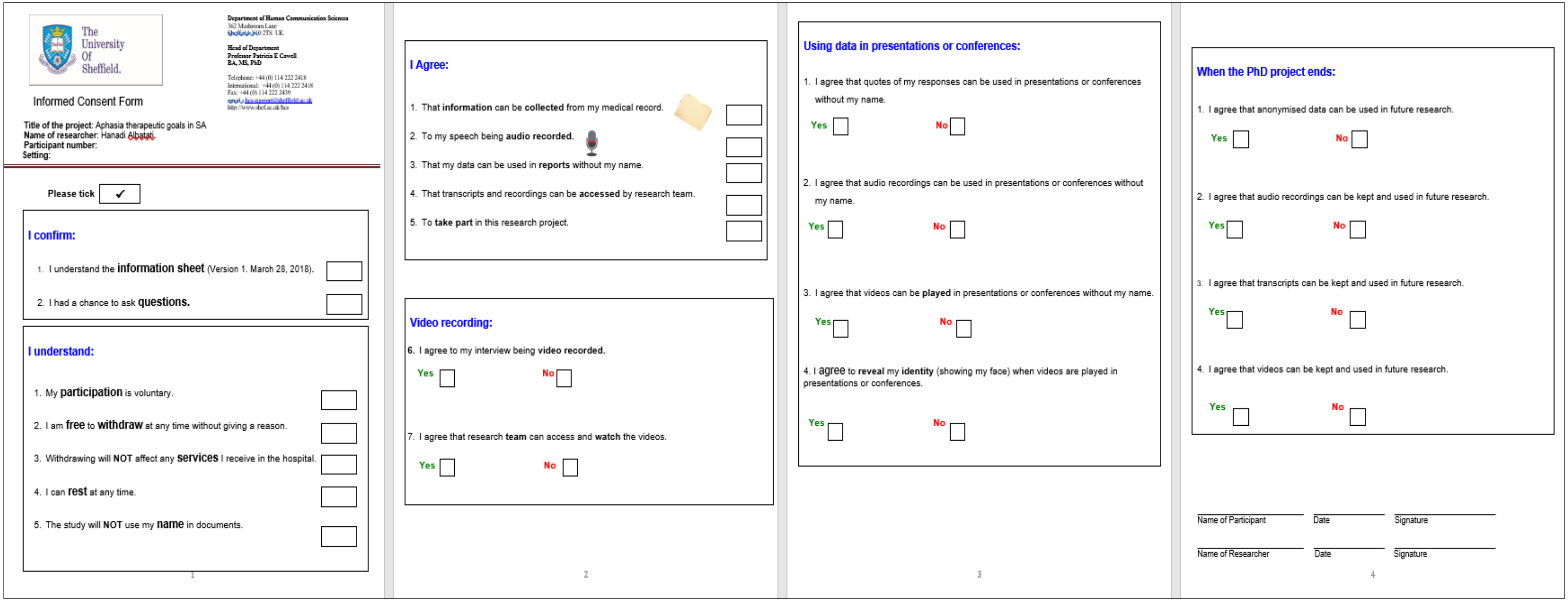
Dr. Catherine Tattersall
Departmental Director of Learning and Teaching
Department of Human Communication Sciences
University of Sheffield
362 Mushroom Lane
Sheffield
S10 2TS

Head of Department

Prof. Patricia E Cowell
Department of Human Communication Sciences
University of Sheffield
362 Mushroom Lane
Sheffield
S10 2TS
United Kingdom
Tel: +44 (0) 114 222 2426
Email: p.e.cowell@sheffield.ac.uk

Thank you for your time

Aphasia-friendly consent form



The University Of Sheffield.

Department of Human Communication Sciences
362 Mushroom Lane
Sheffield S10 2TS UK

Head of Department
Professor Patricia E Cowell
BA, MS, PhD

Telephone: +44 (0) 114 222 2418
International: +44 (0) 114 222 2418
Fax: +44 (0) 114 222 2439
email: hcs-support@sheffield.ac.uk
http://www.shef.ac.uk/hcs

Informed Consent Form

Title of the project: Aphasia therapeutic goals in SA
Name of researcher: Hanadi Albatati
Participant number:
Setting:

Please tick ✓

I confirm:

1. I understand the **information sheet** (Version 1. March 28, 2018). ☐
2. I had a chance to ask **questions.** ☐

I understand:

1. My **participation** is voluntary. ☐
2. I am **free** to **withdraw** at any time without giving a reason. ☐
3. Withdrawing will **NOT** affect any **services** I receive in the hospital. ☐
4. I can **rest** at any time. ☐
5. The study will **NOT** use my **name** in documents. ☐

1

I Agree:

1. That **information** can be **collected** from my medical record. ☐
2. To my speech being **audio recorded.** ☐
3. That my data can be used in **reports** without my name. ☐
4. That transcripts and recordings can be **accessed** by research team. ☐
5. To **take part** in this research project. ☐

Video recording:

6. I agree to my interview being **video recorded.**

Yes ☐ **No** ☐

7. I agree that research **team** can access and **watch** the videos.

Yes ☐ **No** ☐

2

Using data in presentations or conferences:

1. I agree that quotes of my responses can be used in presentations or conferences without my name.

Yes ☐ **No** ☐

2. I agree that audio recordings can be used in presentations or conferences without my name.

Yes ☐ **No** ☐

3. I agree that videos can be **played** in presentations or conferences without my name.

Yes ☐ **No** ☐

4. I **agree** to **reveal** my **identity** (showing my face) when videos are played in presentations or conferences.

Yes ☐ **No** ☐

3

When the PhD project ends:

1. I agree that anonymised data can be used in future research.

Yes ☐ **No** ☐

2. I agree that audio recordings can be kept and used in future research.

Yes ☐ **No** ☐

3. I agree that transcripts can be kept and used in future research.

Yes ☐ **No** ☐

4. I agree that videos can be kept and used in future research.

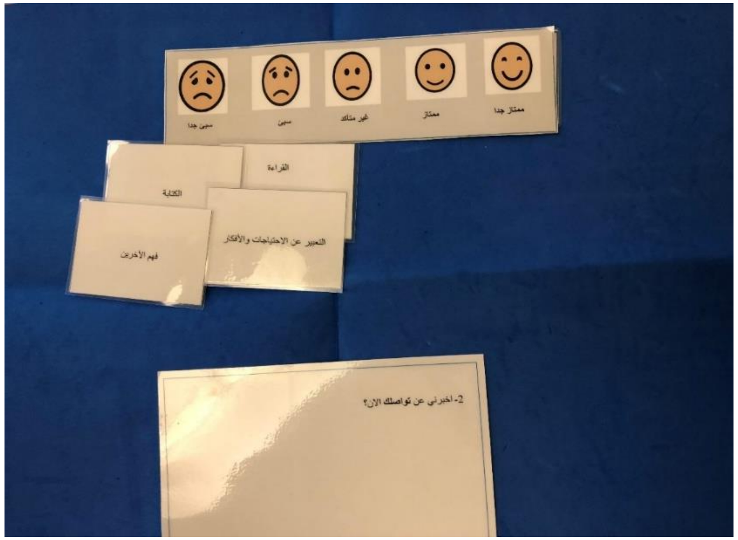
Yes ☐ **No** ☐

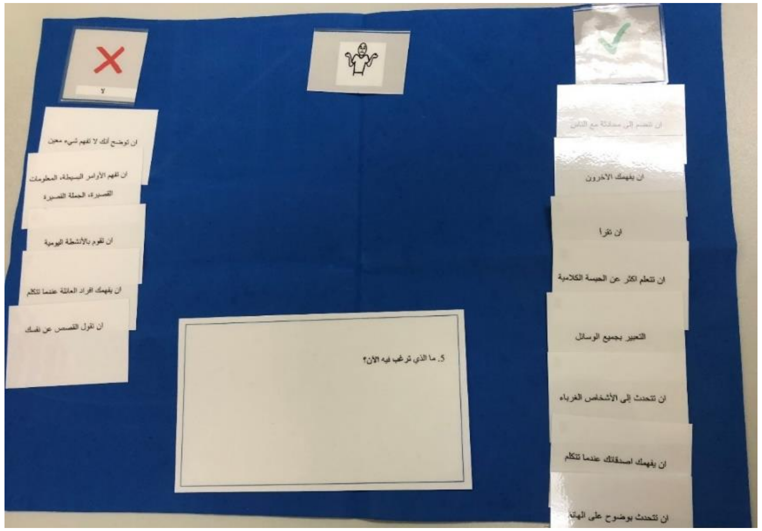
Name of Participant ______ Date ______ Signature ______

Name of Researcher ______ Date ______ Signature ______

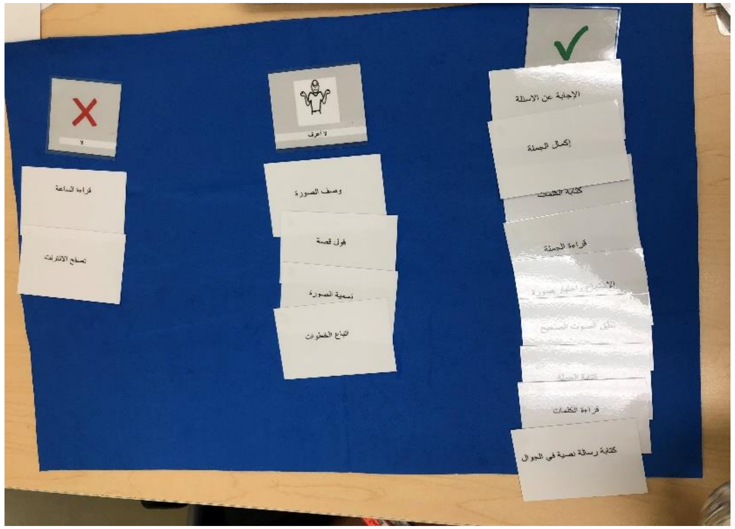
4

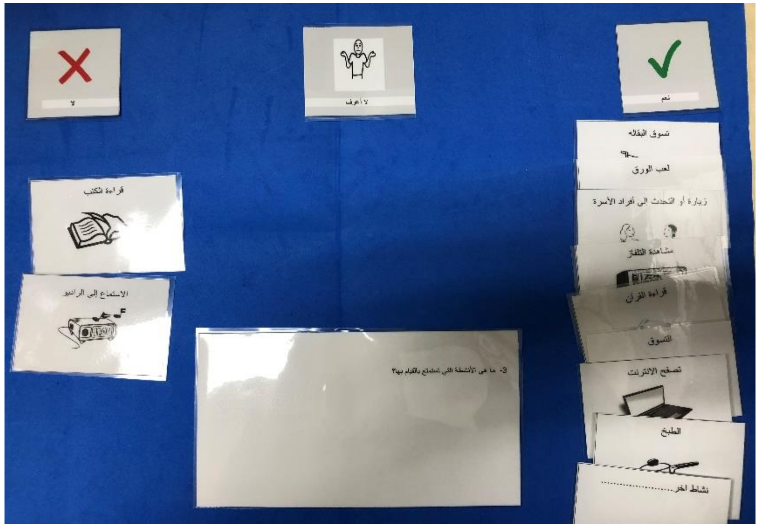
Appendix I: Photos of aphasia-friendly interview materials





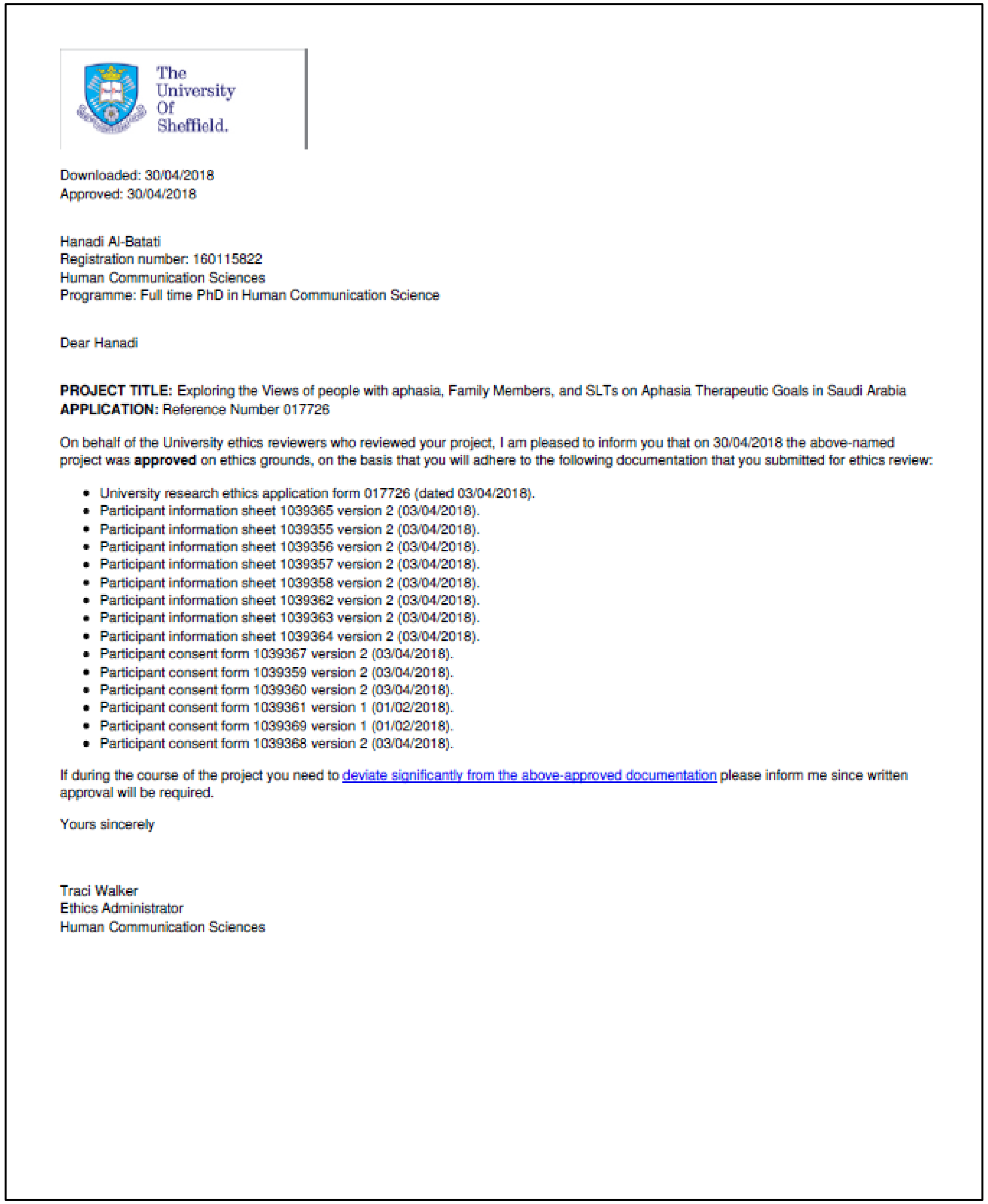
ليس مهماً ___1_________2_________3_________4_________5___ مهم جداً





لا تقدم ___1_________2_________3_________4_________5___ تقدم ملحوظ

Appendix J: Ethical approval letters to conduct the study



The University Of Sheffield.

Downloaded: 30/04/2018
Approved: 30/04/2018

Hanadi Al-Batati
Registration number: 160115822
Human Communication Sciences
Programme: Full time PhD in Human Communication Science

Dear Hanadi

PROJECT TITLE: Exploring the Views of people with aphasia, Family Members, and SLTs on Aphasia Therapeutic Goals in Saudi Arabia
APPLICATION: Reference Number 017726

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 30/04/2018 the above-named project was **approved** on ethics grounds, on the basis that you will adhere to the following documentation that you submitted for ethics review:

- University research ethics application form 017726 (dated 03/04/2018).
- Participant information sheet 1039365 version 2 (03/04/2018).
- Participant information sheet 1039355 version 2 (03/04/2018).
- Participant information sheet 1039356 version 2 (03/04/2018).
- Participant information sheet 1039357 version 2 (03/04/2018).
- Participant information sheet 1039358 version 2 (03/04/2018).
- Participant information sheet 1039362 version 2 (03/04/2018).
- Participant information sheet 1039363 version 2 (03/04/2018).
- Participant information sheet 1039364 version 2 (03/04/2018).
- Participant consent form 1039367 version 2 (03/04/2018).
- Participant consent form 1039359 version 2 (03/04/2018).
- Participant consent form 1039360 version 2 (03/04/2018).
- Participant consent form 1039361 version 1 (01/02/2018).
- Participant consent form 1039369 version 1 (01/02/2018).
- Participant consent form 1039368 version 2 (03/04/2018).

If during the course of the project you need to deviate significantly from the above-approved documentation please inform me since written approval will be required.

Yours sincerely

Traci Walker
Ethics Administrator
Human Communication Sciences

Kingdom of Saudi Arabia
Ministry of Health
King Fahad Medical City
(162)

المملكة العربية السعودية
وزارة الصحة
مدينة الملك فهد الطبية
(١٦٢)

IRB Registration Number with KACST, KSA: H-01-R-012
IRB Registration Number with OHRP/NIH, USA: IRB00010471
Approval Number Federal Wide Assurance NIH, USA: FWA00018774

May 23, 2018
IRB Log Number: 18-252E
Department: External
Category of Approval: EXEMPT

Dear Hanadi Albatati,

I am pleased to inform you that your submission dated May 14, 2018 for the study titled '**Exploring the Views of People with Aphasia, Family Members, and SLTs on Aphasia Therapeutic Goals in Saudi Arabia**' was reviewed and was approved according to ICH GCP guidelines. Please note that this approval is from the research ethics perspective only. You will still need to get permission from the head of department or unit in KFMC or an external institution to commence data collection.

We wish you well as you proceed with the study and request you to keep the IRB informed of the progress on a regular basis, using the IRB log number shown above.

Please be advised that regulations require that you submit a progress report on your research every 6 months. You are also required to submit any manuscript resulting from this research for approval by IRB before submission to journals for publication.

As a researcher you are required to have current and valid certification on protection human research subjects that can be obtained by taking a short online course at the US NIH site or the Saudi NCBE site followed by a multiple choice test. Please submit your current and valid certificate for our records. Failure to submit this certificate shall a reason for suspension of your research project.

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

Sincerely yours,

Prof. Omar H. Kasule
Chairman, Institutional Review Board (IRB)
King Fahad Medical City, Riyadh, KSA
Tel: + 966 1 288 9999 Ext. 26913
E-mail: okasule@kfmc.med.sa

K F M C
Approved
23 MAY 2018
I R B

P.O. Box 64399 Riyadh 11536 Saudi Arabia
Telephone 966 11 562 0000 Fax 966 11 562 0236

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

1st July 2018

Ms. Hanadi Albatati
Primary Investigator
PhD Student
University of Sheffield
362 NMushroom Lane
Sheffield S10 2TS U.K.
Human Communication Sciences
c/o King Abdulaziz University, Jeddah, KSA

Subject : **Your Research Title: "Exploring the iew of People with Aphasia, Family Members, and SLT's Aphasia Therapeutic Goals in Saudi Arabia".**

Dear Ms. Hanadi Albatati,

I am pleased to inform about the approval of the above-mentioned research proposal **on 1st July 2018**, with below pointers to be followed due to some revisions were been taken into consideration upon proceeding to your data collections:

Total period of data collection: Approximately 8 weeks
Start date: Any time 15 July 2018
End date: 8 weeks

Assessment Intervention Tools to be conducted –

- **Phase 1, Pilot phase, Phase 2, semi structured and in-depth interviews.**
- **Study involves two forms of data collections, data extractions, from patient case notes, and one to one interview.**

Kindly present this letter to the head/manager of the department/rehab ward in which data will be collected. The head/manger has the authority to do all needed arrangement to facilitate data collection. You are advised to quote the project number indicated herein in all transactions and communications. You are advised to submit a progress report, this time after three (3) months from approval of your research proposal, in relation to this research schemed we need you also to send us a final report after your research will be completed in relation to this research schemed to update the committee of its results. **You may informed that, for each participant from SBAHC, you will be strictly required to copy the signed consent form and hand it to the nurse to be added to their medical file.**

I trust you research scheme proves fruitful and beneficial to you, the patients and this institution.

Your research protocol has now been documented under:

Project Number: 031/ 2018/1st July
Series of : 2018 / 1st July

Thank you and best regards.

Sincerely yours,

DR. EIMAN HASSAN ALISMAIL
Chairperson of the Research & Ethics Committee/
Senior Rehabilitation Psychologist
Sultan Bin Abdulaziz Humanitarian City

Appendix K: Screening questions and PWA's responses

Screening questions	Participant 001p response	Participant 002p response
Tell me about your life before aphasia. *Prompt: Did you work? If yes, what did you do?*	001p reported that she is a housewife.	*002p: "I was in the traffic police for about 20 years or 22 years and I left them, and I am working now only in a private job."*
Tell me about your family. *Prompt 1: Do you have kids? If yes, how many?* *Prompt 2: Do you have brothers and sisters? If yes, how many?*	001p reported that she has two girls and two boys who are not married, and has two girls and three boys who are married. Furthermore, she reported that she has two brothers and four sisters.	*002p: "I have two and five kids. Two are married and three are here."*
What activities do you enjoy doing?	001p chose all items that were presented on Talking Mats^{TM} as preferred activities (except for using the Internet and playing cards). She chose reading books, watching TV, reading the Quran, visiting family, cooking, and grocery shopping. Moreover, 001p reported that she enjoys household duties.	002p: "Honestly, I don't have because if I go out, I go out of Saudi. I go out with kids or alone and I come back." Through the use of Talking MatsTM, 002p chose reading books, watching TV, reading the Quran and visiting family as activities that he loves to undertake. 002p chose the Internet, playing cards, cooking, and grocery shopping as activities that he undertakes sometimes, and shopping as an activity that he does not like.

Appendix L: Pilot screening

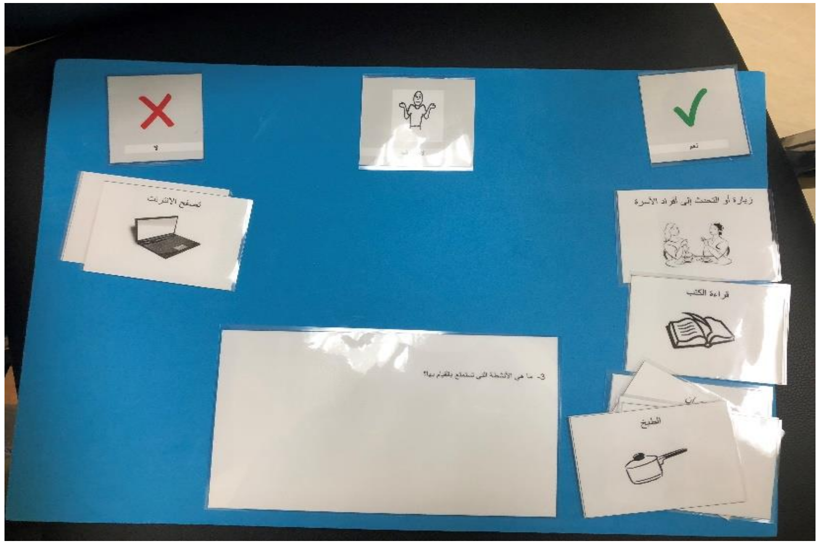


Photo of 001p’s response using Talking Mats^{TM} during the screening

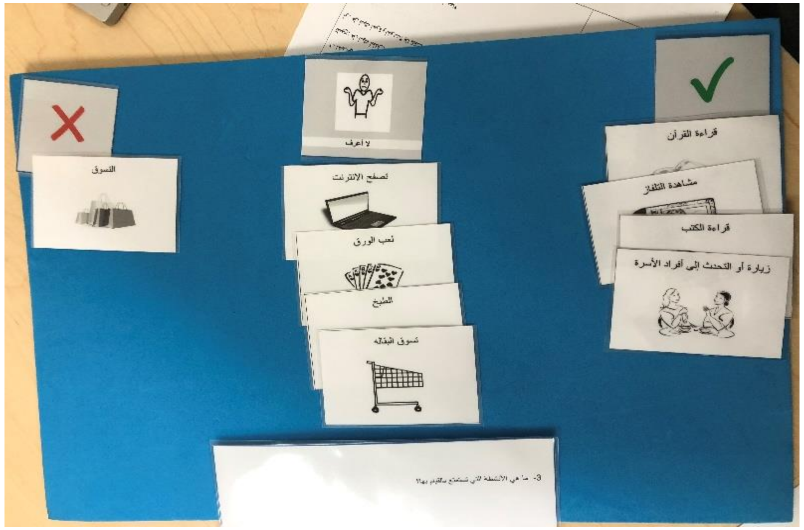


Photo of 002p’s response using Talking Mats^{TM} during the screening

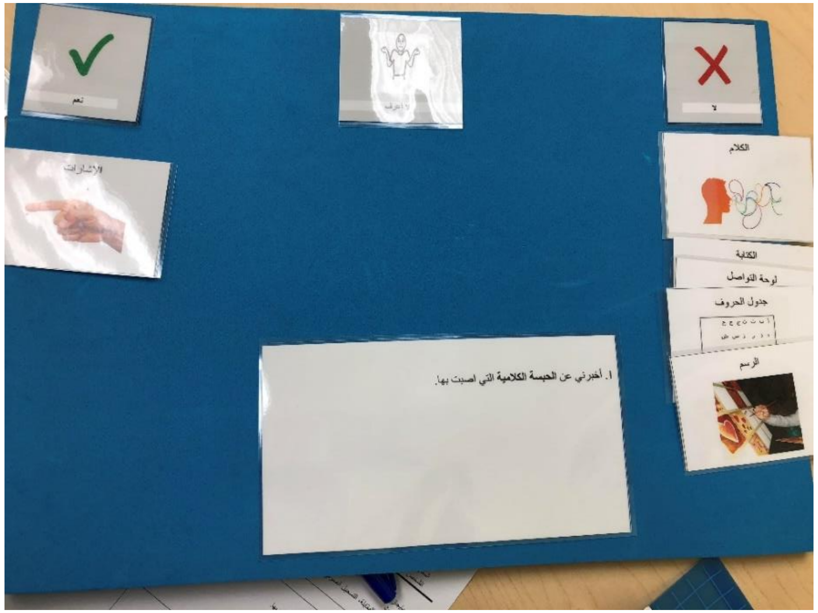
Appendix M: Pilot interview questions and PWA's responses

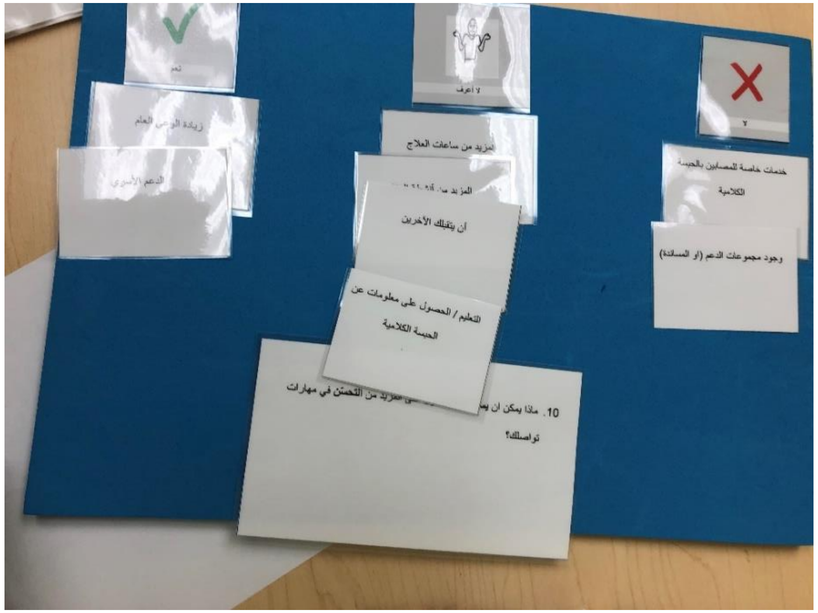
Interview questions	Participant 001p response	Participant 002p response
Experience with condition Tell me about your aphasia. *Prompt: your communication.*	001p reported that she woke up and could not speak. She attended the hospital with her son and then they found out about the stroke. With the help of Talking Mats^{TM}, 001p expressed that her comprehension was good when she first experienced stroke, but that her expression was not, and that she used to sign when she could not communicate through speaking.	*002p: "When I first had it I spoke nothing for three days."* 002p expressed that, with the help of Talking Mats^{TM}, his expression, reading and writing were poor when he first experienced stroke, while his comprehension was good. Moreover, 002p reported that he used to sign when he could not express.
Experience with services Tell me about the speech and language therapy you had before.	001p reported that the current therapy is her first speech and language therapy. She expressed that, with the help of Talking Mats^{TM} , she worked on finding words, listening and comprehension, sentences, and reading.	*002p: "I came to [SLT's name]."* 002p expressed that he started speech and language therapy at KFMC when he first experienced stroke, and that he continues to receive therapy. With the help of Talking Mats^{TM}, 002p expressed that he worked to improve different skills such as finding words, completing sentences, and writing, albeit not telling stories.
Desired goals What did you want or hope when you first had aphasia? What are your goals now? *Prompt: What do you want/hope/desire now?*	-001p reported that speaking was what she wanted when she first experienced stroke. With the help of Talking Mats^{TM}, 001p expressed more goals including "To make your family members understand you when you talk" and "To speak clearly on the phone". 001p reported that her goal now is to express by speaking.	*002p: "When it first happened, honestly, I mean, honestly, thanks to God, when I noticed that I was better — just to see them."* 002p expressed that the only thing that he wanted was to see his family after the stroke. 002p expressed that his goal now is to speak. With the help of Talking Mats^{TM}, the participant reported goals including reading, writing, finding words, and speaking clearly on the phone.

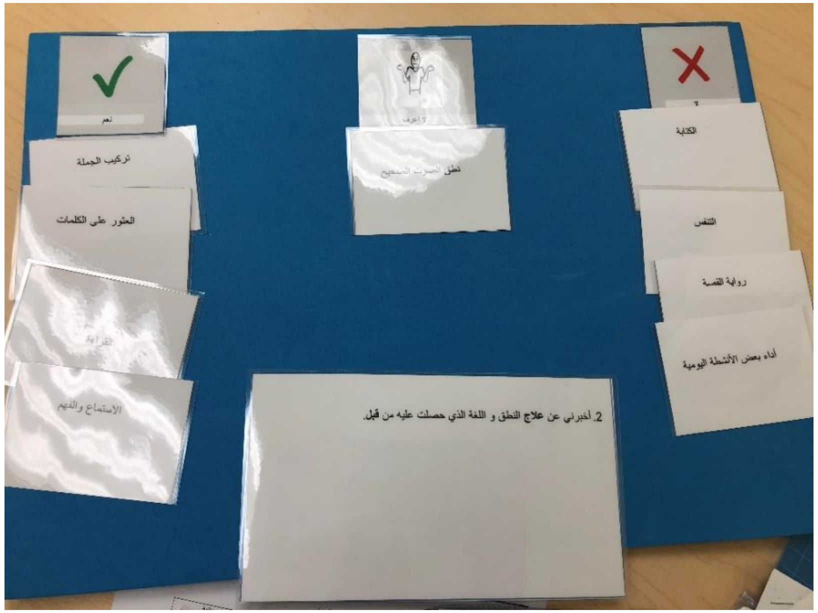
Current therapeutic goals Do you work in speech and language therapy to achieve these goals? (in relation to the previous question) *Clarification probes:* *If yes, what activities do you do in therapy?* *If no, what do you do in speech and language therapy now and why?*	001p reported that she works on improving speaking and comprehension in the sessions, but not reading and writing. 001p reported that some activities included pictures of fruit and vegetables and working at the level of words and sentences. With the help of Talking Mats^{TM}, 001p expressed that she works on activities including naming pictures, completing sentences, and answering questions.	*002p: "We go through all activities until I talk."* With the help of Talking Mats^{TM}, 002p expressed that he works on activities including answering questions, listening and choosing words, and texting.
Goal-setting process, involvement, and influential factors Who chose your goals for speech and language therapy? Did you help your SLT to choose goals? *Clarification probes:* *If yes, how?* *If no, why?* Do you think it is important to help your SLTs in choosing goals?	001p reported that the SLT identified the goals by himself. 001p reported that she did not help the SLT in setting the goals because what she wanted was to improve her speech and this was already recognised by the SLT. 001p reported that it is not important at all (1/5) to help the SLT in setting the goals because the SLT knows better and knows the case in detail.	002p reported that the SLT identified the goals by herself. 002p reported that he did not help the SLT in setting the goals because *"she knows all",* as he expressed. 002p reported that it is not important to help the SLT in setting the goals.

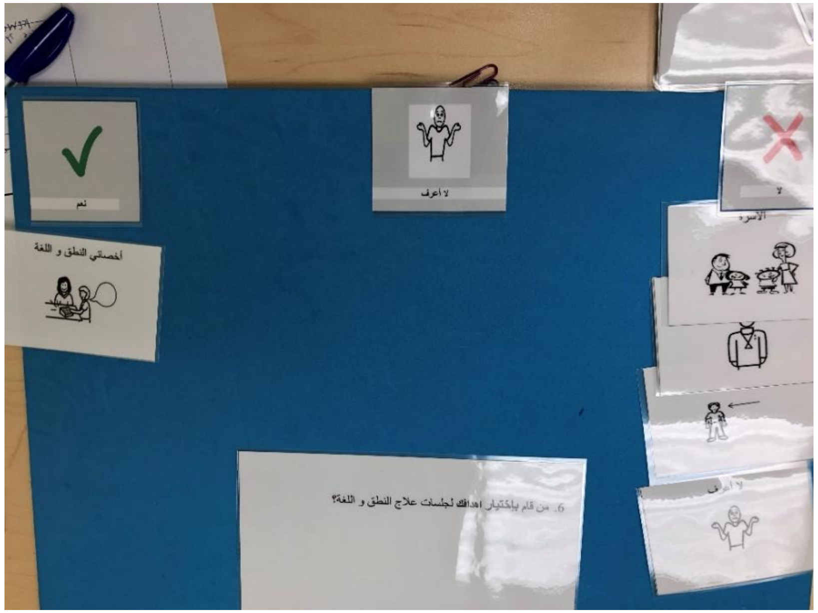
Clarification probes: *If yes, why?* *If no, why?*		
Communication skills and progress Do you notice any progress in your communication with therapy? *Clarification probes:* *If yes, tell me more about it.* *If no, why?* What might help you for further improvement in your communication?	001p reported that she is noticing improvement in her communication (4/5). With the help of Talking Mats^{TM}, 001p reported that increasing public awareness and family support are factors for further improvement.	002p expressed that he has been noticing an improvement in his communication since he first experienced stroke (5/5). When asked about things that could help for further improvement, 002p reported that going out and interacting with others helps. *002p: "With audience, we go outside; everything goes, thanks to God, it is good, I mean."*

Appendix N: Pilot interviewing (001p’s responses using aphasia-friendly materials)

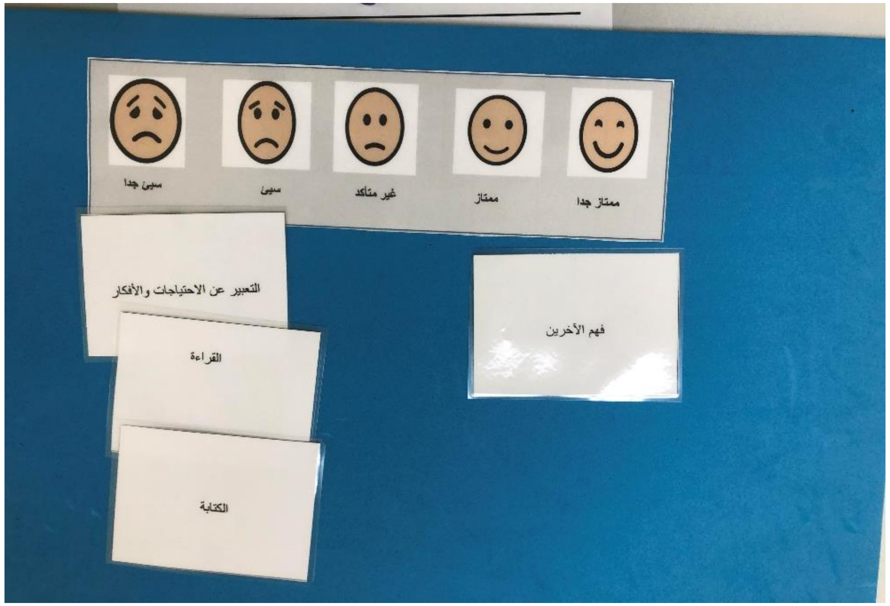


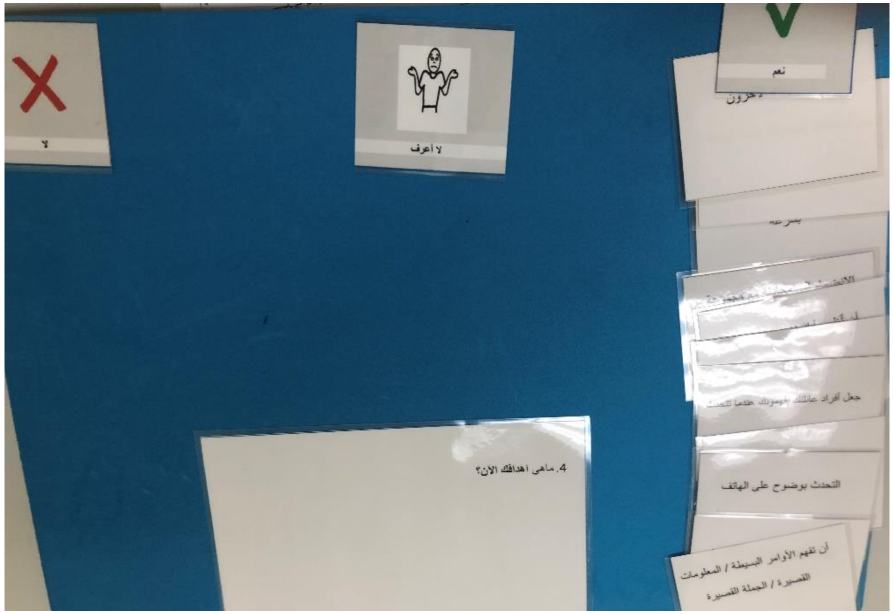


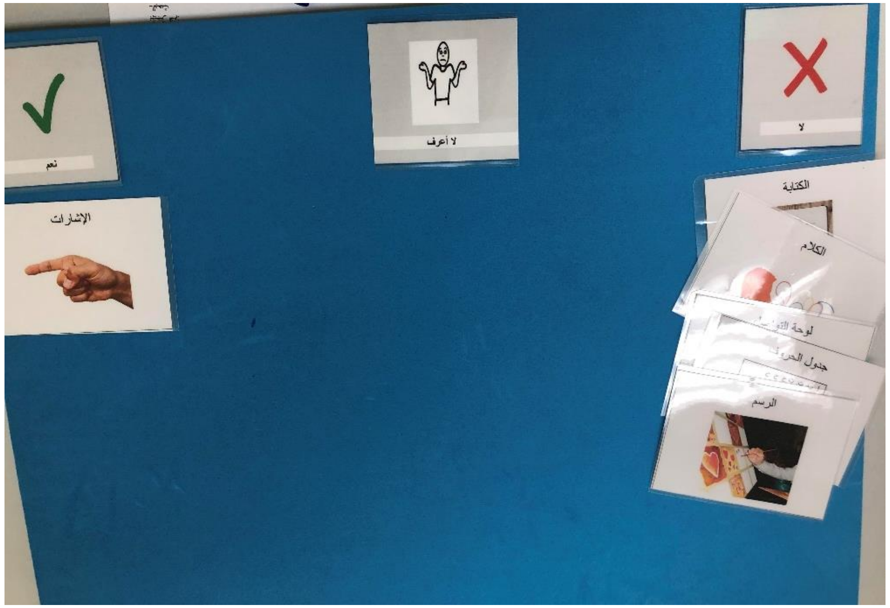


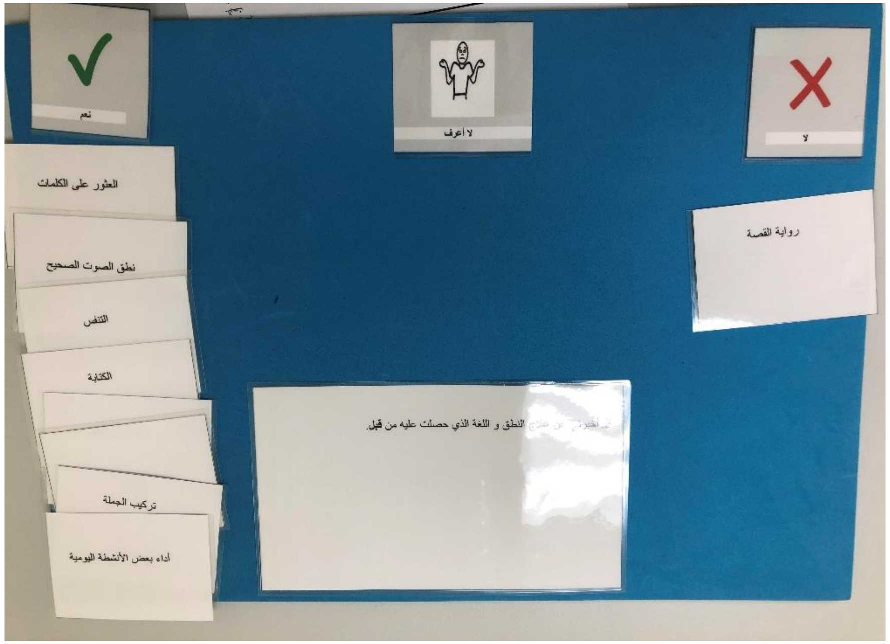


Pilot interviewing: (002p's responses using aphasia-friendly materials)

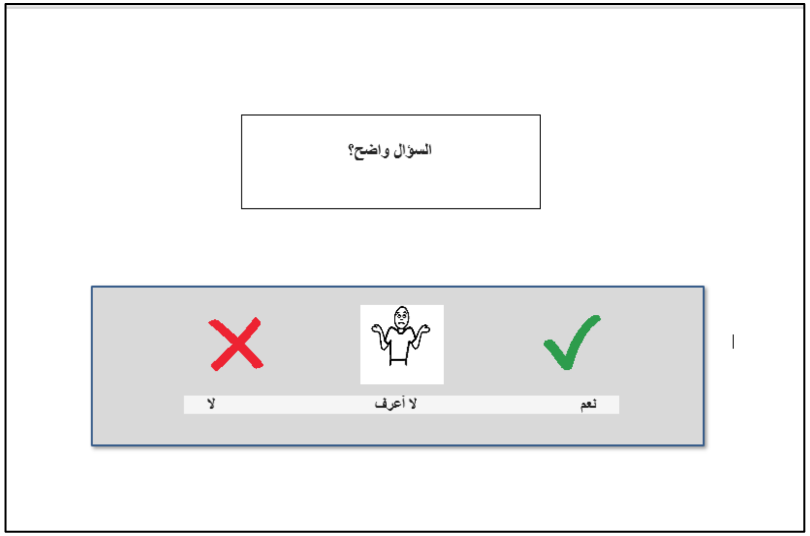






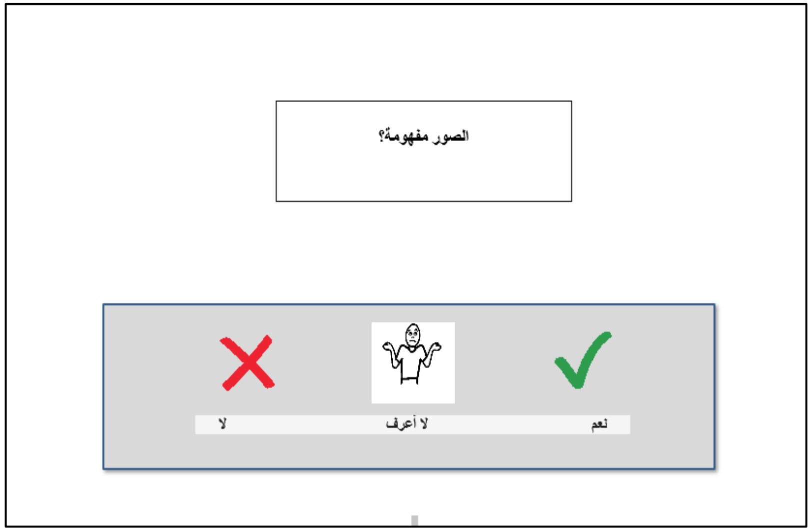


Appendix O: Aphasia-friendly feedback materials



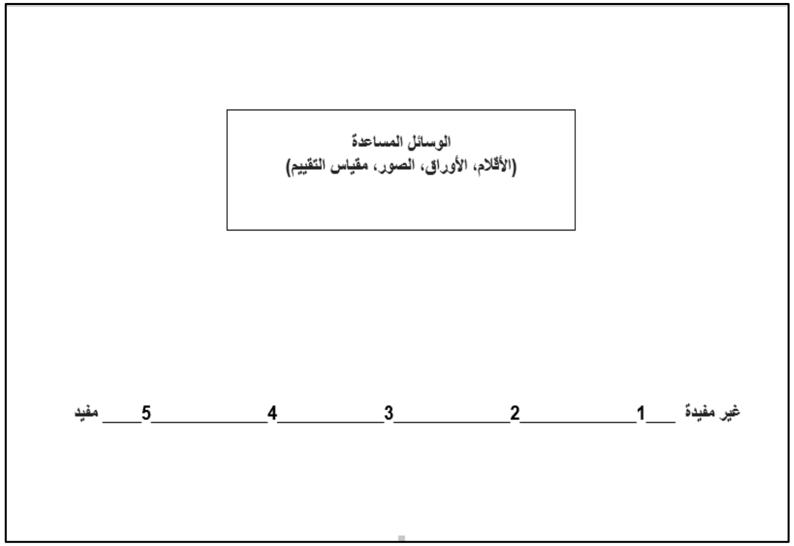
السؤال واضح؟

لا ✗ | لا أعرف | نعم ✓



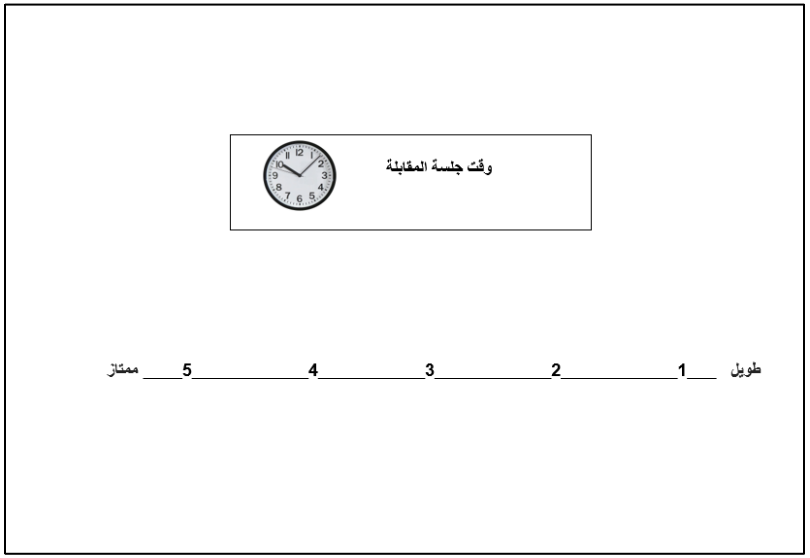
الصور مفهومة؟

لا ✗ | لا أعرف | نعم ✓



الوسائل المساعدة
(الأقلام، الأوراق، الصور، مقياس التقييم)

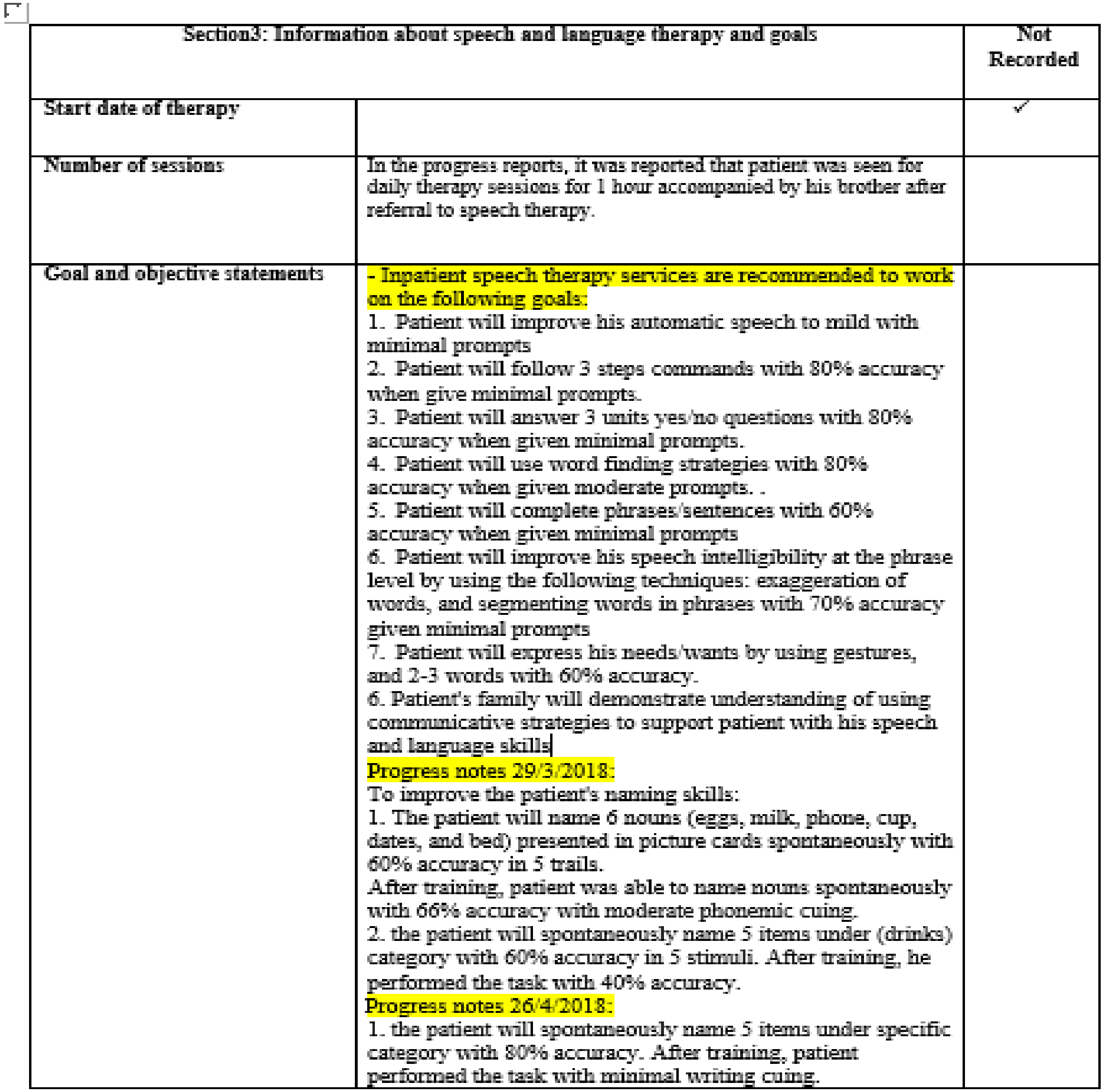
غير مفيدة ___1___________2___________3___________4___________5____ مفيد



وقت جلسة المقابلة

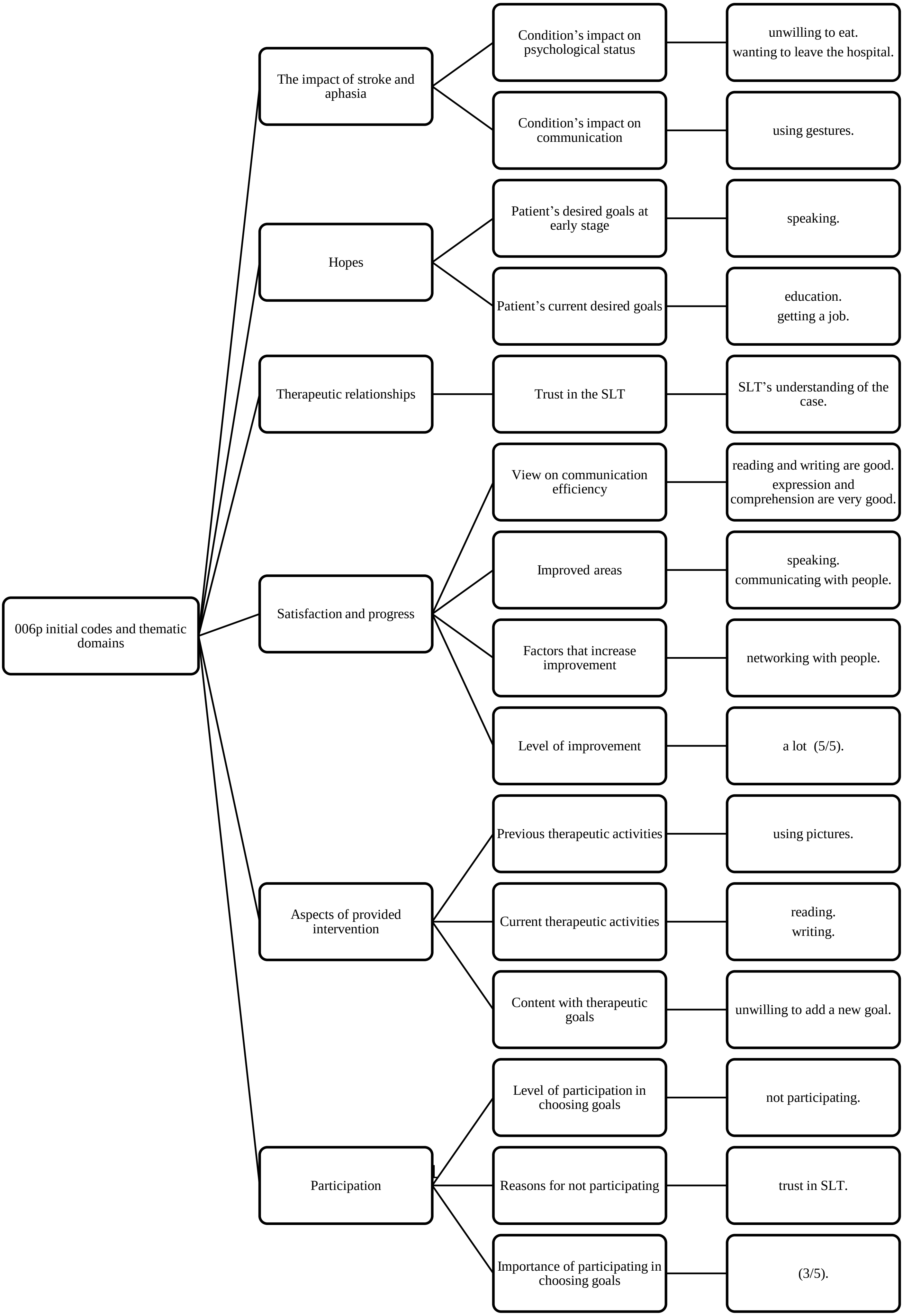
طويل ___1___________2___________3___________4___________5____ ممتاز

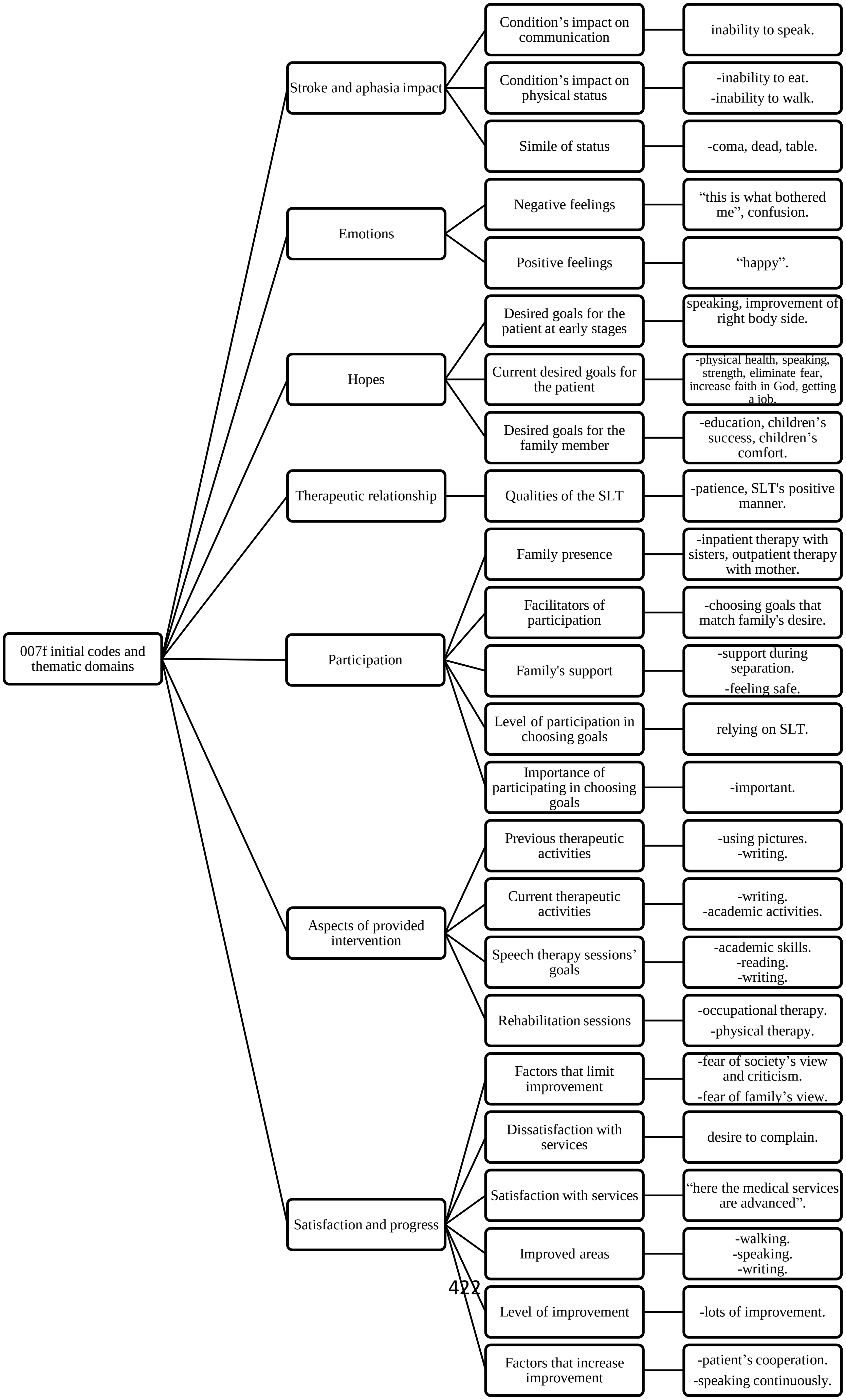
Appendix P: Completed section 3 from participant 002p's case record data extraction form

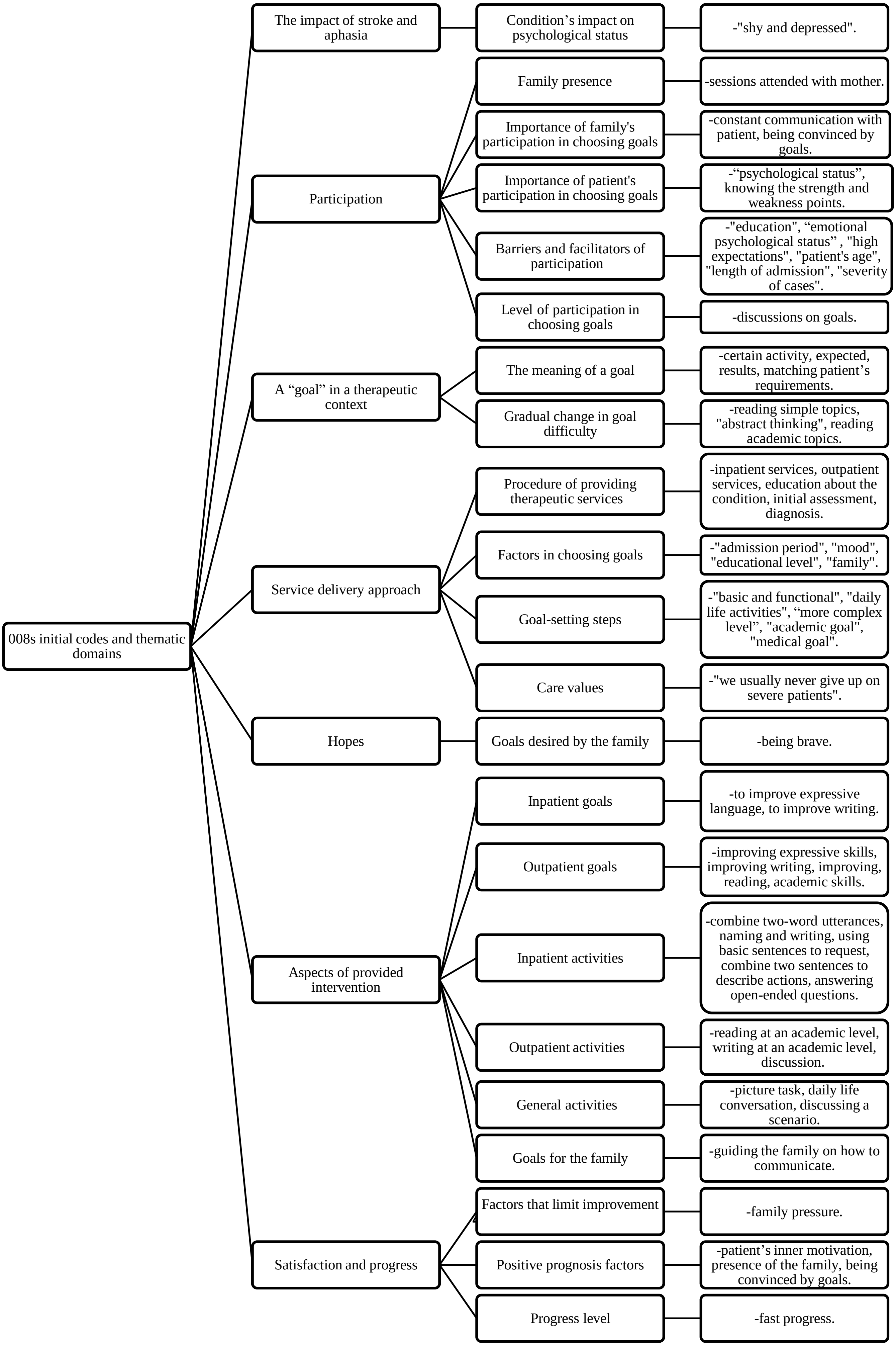


Section3: Information about speech and language therapy and goals		Not Recorded
Start date of therapy		✓
Number of sessions	In the progress reports, it was reported that patient was seen for daily therapy sessions for 1 hour accompanied by his brother after referral to speech therapy.	
Goal and objective statements	- Inpatient speech therapy services are recommended to work on the following goals: 1. Patient will improve his automatic speech to mild with minimal prompts 2. Patient will follow 3 steps commands with 80% accuracy when give minimal prompts. 3. Patient will answer 3 units yes/no questions with 80% accuracy when given minimal prompts. 4. Patient will use word finding strategies with 80% accuracy when given moderate prompts. . 5. Patient will complete phrases/sentences with 60% accuracy when given minimal prompts 6. Patient will improve his speech intelligibility at the phrase level by using the following techniques: exaggeration of words, and segmenting words in phrases with 70% accuracy given minimal prompts 7. Patient will express his needs/wants by using gestures, and 2-3 words with 60% accuracy. 6. Patient's family will demonstrate understanding of using communicative strategies to support patient with his speech and language skills Progress notes 29/3/2018: To improve the patient's naming skills: 1. The patient will name 6 nouns (eggs, milk, phone, cup, dates, and bed) presented in picture cards spontaneously with 60% accuracy in 5 trails. After training, patient was able to name nouns spontaneously with 66% accuracy with moderate phonemic cuing. 2. the patient will spontaneously name 5 items under (drinks) category with 60% accuracy in 5 stimuli. After training, he performed the task with 40% accuracy. Progress notes 26/4/2018: 1. the patient will spontaneously name 5 items under specific category with 80% accuracy. After training, patient performed the task with minimal writing cuing.	

Appendix Q: Initial codes and thematic domains for 006p, 007f, and 008s




007f initial codes and thematic domains
Stroke and aphasia impact
Condition’s impact on communication
inability to speak.
Condition’s impact on physical status
-inability to eat.
-inability to walk.
Simile of status
-coma, dead, table.
Emotions
Negative feelings
“this is what bothered me”, confusion.
Positive feelings
“happy”.
Hopes
Desired goals for the patient at early stages
speaking, improvement of right body side.
Current desired goals for the patient
-physical health, speaking, strength, eliminate fear, increase faith in God, getting a job.
Desired goals for the family member
-education, children’s success, children’s comfort.
Therapeutic relationship
Qualities of the SLT
-patience, SLT's positive manner.
Participation
Family presence
-inpatient therapy with sisters, outpatient therapy with mother.
Facilitators of participation
-choosing goals that match family's desire.
Family's support
-support during separation.
-feeling safe.
Level of participation in choosing goals
relying on SLT.
Importance of participating in choosing goals
-important.
Aspects of provided intervention
Previous therapeutic activities
-using pictures.
-writing.
Current therapeutic activities
-writing.
-academic activities.
Speech therapy sessions’ goals
-academic skills.
-reading.
-writing.
Rehabilitation sessions
-occupational therapy.
-physical therapy.
Satisfaction and progress
Factors that limit improvement
-fear of society’s view and criticism.
-fear of family’s view.
Dissatisfaction with services
desire to complain.
Satisfaction with services
“here the medical services are advanced”.
Improved areas
-walking.
-speaking.
-writing.
Level of improvement
-lots of improvement.
Factors that increase improvement
-patient’s cooperation.
-speaking continuously.



008s initial codes and thematic domains

The impact of stroke and aphasia	Condition’s impact on psychological status	-"shy and depressed".
Participation	Family presence	-sessions attended with mother.
	Importance of family's participation in choosing goals	-constant communication with patient, being convinced by goals.
	Importance of patient's participation in choosing goals	-“psychological status”, knowing the strength and weakness points.
	Barriers and facilitators of participation	-"education", “emotional psychological status” , "high expectations", "patient's age", "length of admission", "severity of cases".
	Level of participation in choosing goals	-discussions on goals.
A “goal” in a therapeutic context	The meaning of a goal	-certain activity, expected, results, matching patient’s requirements.
	Gradual change in goal difficulty	-reading simple topics, "abstract thinking", reading academic topics.
Service delivery approach	Procedure of providing therapeutic services	-inpatient services, outpatient services, education about the condition, initial assessment, diagnosis.
	Factors in choosing goals	-"admission period", "mood", "educational level", "family".
	Goal-setting steps	-"basic and functional", "daily life activities", “more complex level”, "academic goal", "medical goal".
	Care values	-"we usually never give up on severe patients".
Hopes	Goals desired by the family	-being brave.
Aspects of provided intervention	Inpatient goals	-to improve expressive language, to improve writing.
	Outpatient goals	-improving expressive skills, improving writing, improving, reading, academic skills.
	Inpatient activities	-combine two-word utterances, naming and writing, using basic sentences to request, combine two sentences to describe actions, answering open-ended questions.
	Outpatient activities	-reading at an academic level, writing at an academic level, discussion.
	General activities	-picture task, daily life conversation, discussing a scenario.
	Goals for the family	-guiding the family on how to communicate.
Satisfaction and progress	Factors that limit improvement	-family pressure.
	Positive prognosis factors	-patient’s inner motivation, presence of the family, being convinced by goals.
	Progress level	-fast progress.