

**Swallowing Changes in People with Parkinson's in Saudi Arabia:
Perceptions and Practices**

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Abstract

The aim of this research was to explore the experience of swallowing changes in people with Parkinson's (PwP) in Saudi Arabia and their impact on both PwP and their families.

The impact of eating and drinking changes in neurological conditions has not been thoroughly studied and the influence of culture on how people deal and cope with swallowing changes also has been neglected. There are very few studies on Parkinson's carried out in Saudi Arabia and none have looked at the impact of these changes on both the PwP and their families.

This is a qualitative study, using semi-structured interviews with 39 participants PwP and their carers and a focus group with three speech and language therapists. The interviews and focus group were transcribed verbatim, translated into English and were analysed using thematic analysis.

The main themes categories that emerged are 'the whole meal is awkward', 'we all have Parkinson's' and 'I leave it all to Allah'. There was a close link between cultural context and how eating and drinking changes manifested and impacted on individuals and families. The role of the older person in Saudi culture during meals as well as gender roles within a Saudi family strongly influenced how PwP felt about their restricted eating abilities. The influence of Islamic beliefs was apparent in both the PwP and the caregivers' interviews. It shaped how they dealt with Parkinson's, how they interpreted symptoms and change, their views on rehabilitation and their willingness to discuss the impact of changes with the interviewer.

This study highlights how Saudi Arabian society has traditional mealtime customs for families and for older people in particular. Eating and drinking changes due to Parkinson's challenge and restrict these customs. An understanding of these socio-cultural factors is necessary to appreciate how the impact of eating and drinking changes in Saudi Arabia differs from impacts reported for European and North American populations and the different implications this holds for rehabilitation of PwP. Speech and language therapists as well as other healthcare workers need to be aware of the cultural background of the person with Parkinson's when assessing their eating and drinking abilities. Considerations have to be made when recommending treatment plans or eating modifications.

This thesis is dedicated to Mariam Aljardan and Mohammed Alhussain,
my beloved parents

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Table of Contents

Abstract.....	iii
Acknowledgements	v
Table of Contents	vii
List of Tables and Figures	xi
Chapter 1. Introduction, Importance, and Structure	1
1.1 Introduction.....	1
1.2 Motivation and Importance.....	2
1.3 Structure of the Thesis	4
Chapter 2. Literature Review.....	5
2.1 Parkinson's	5
2.1.1 An Overview	5
2.1.2 Prevalence	6
2.1.3 Symptoms and Diagnosis	7
2.1.4 Management	11
2.2 Issues Associated with Parkinson's.....	13
2.2.1 Dysphagia.....	13
2.2.2 The multi-layered nature of Parkinson's	15
2.2.3 The psychosocial impact of dysphagia and Parkinson's	17
2.3 The Cultural Context of Health Research.....	21
2.4 Saudi Arabia	22
2.4.1 The Saudi Arabian culture and health and illness	29
2.4.2 An overview of the health system in Saudi Arabia.....	30
2.5 Research Questions and Study Objectives.....	31
2.5.1 Purpose of the Study	31
2.5.2 Research Questions	31
2.5.3 Research Objectives	31
2.6 Summary	32

Chapter 3. Methodology and Methods	33
3.1 Philosophical Assumptions.....	33
3.2 Study Design.....	37
3.3 Sampling	39
3.3.1 Recruitment	41
3.3.2 Participants with Parkinson's.....	45
3.3.3 Carers	46
3.4 Speech and Language Therapists Focus Group.....	47
3.5 The Interview Process.....	48
3.5.1 Reflecting on the Interviews	50
3.6 Data collection challenges	52
3.6.1 Issues with recruitment.....	52
3.6.2 Issues with interviewing people with Parkinson's	53
3.7 Data Preparation and Analysis.....	54
3.7.1 Transcribing and translation.....	55
3.7.2 Reading.....	55
3.7.3 Coding and building the themes list.....	56
3.7.4 Evaluating the quality of qualitative research	56
3.8 Ethical Review and Approval	58
3.9 Conclusion	59
Chapter 4. Findings	61
4.1 Findings from first stage of fieldwork	62
4.1.1 Eating and drinking changes Vs swallowing changes	62
4.1.2 Carers interviews (family and social lives).....	67
4.1.3 Findings from SLTs focus group	71
4.1.4 Reflecting on the first stage of fieldwork.....	76
4.2 The Study Themes	78
4.3 Theme One: The Whole Meal is Awkward.....	81

4.3.1 Physiological eating and drinking changes and their effects	82
4.3.2 Social impact of eating and drinking changes.....	87
4.3.3 The emotional impact of eating and drinking changes	96
4.4 Theme two: We all have Parkinson's	103
4.4.1 Carers' experiences.....	103
4.4.2 The family's experience.....	112
4.4.3 Relatives (distant family)	113
4.5 Theme three: I leave it all to Allah (Religious, Cultural and Health Service Policies)	118
4.5.1 Ibtala	118
4.5.2 Transportation	120
4.5.3 Gender segregation.....	121
4.5.4 Understanding Parkinson's and the changes that accompany it	122
4.5.5 Health Service Organisations and Availability	124
4.6 Summary	128
Chapter 5. Discussion and Conclusion	129
5.1 Introduction.....	129
5.2 Reflections during the analysis	130
5.3 The imprint of Saudi Arabian culture on perceived eating and drinking changes.....	130
5.3.1 The experiences of people with Parkinson's	131
5.3.2. Experiences of people with Parkinson's: patients' failure to appreciate the seriousness of their condition and the key role played by Saudi culture	136
5.4. Understanding the main findings in relation to theoretical constructs	138
5.5. The experiences of carers and the influence of gender.....	147
5.6. The role of religion	153
5.7 Implications for clinical practice	156
5.8 Limitations and implications for future research.....	161
5.9 Discussion Summary	167
5.10 Final reflection	167

5.11 Conclusion	169
References and bibliography	171
Glossary	188
Appendices	191
Appendix A: Focus group topic guide	191
Appendix B: People with Parkinson’s Interview Schedule (Initial interviews)	193
Appendix C: People with Parkinson’s Interview Schedule (Final interviews)	197
Appendix D: Carer Interview Schedule (Initial interviews)	200
Appendix E: Carers Interview Schedule (Final interviews)	204
Appendix F: Data Form	206
Appendix G: Ethic approval Newcastle University	208
Appendix H: Information sheet for People with Parkinson’s	209
Appendix I: Information sheet for Carers	215
Appendix J: Consent form for People with Parkinson’s	219
Appendix K: Consent form for Carers	222

List of Tables and Figures

Table 1 Non-motor Symptoms of Parkinson's.....	8
Figure 1 Saudi Arabia map.....	24
Figure 2 Data collection and analysis.....	38
Table 2 Timeline of data collection.....	39
Table 3 People with Parkinson's participants.....	43
Table 4 Carers participants.....	44
Table 5 Checklist for good thematic analysis.....	56
Table 6 Theme 1.....	79
Table 7 Theme 2.....	80
Table 8 Theme 3.....	81
Image 1: A typically miniscule Saudi coffee cup.....	95
Figure 3 The COM-B model adapted from (Michie et al., 2014).	145
Figure 4 The Behavioural Change wheel adopted from (Michie et al., 2011).	146

Chapter 1. Introduction, Importance, and Structure

1.1 Introduction

Studies on the effects of Parkinson's on the lives of patients and their carers have examined physiological, social, and psychological issues. Most research has focused on the physiological symptoms and how to mediate their effects. Parkinson's is a chronic, progressive, neurodegenerative disorder with motor symptoms including tremors, body rigidity, and a slowed ability to start and continue movements (bradykinesia). Recent studies have examined motor and non-motor disturbances in addition to the more commonly recognized issues such as lower quality of life, depression, and anxiety (Jankovic, 2008; Brown *et al.*, 2011; Pfeiffer and Bodis-Wollner, 2013; Kang and Ellis-Hill, 2015; van Uem *et al.*, 2016).

From a speech and language therapy perspective, swallowing is a major focus of treatment, but research is sparse on the overall impact of eating and drinking changes in people with Parkinson's and their families, especially their carers, as a result of these swallowing difficulties. Understanding the implications of changes in eating and drinking as a result of Parkinson's will inform and provide explanations for studies that show non-motor issues in this population. This thesis uses qualitative methods to explore the experiences of eating and drinking changes in the lives of people with Parkinson's and their carers within a Saudi context, thereby addressing the socio-cultural context of dysphagia (swallowing impairment) and how people with Parkinson's experience it in their day-to-day lives.

The current study examines the impact of eating and drinking difficulties on individuals and families in Saudi Arabia. The culture of Saudi Arabia presents unique challenges for Speech and Language Therapists (SLTs) who provide rehabilitation services for people with Parkinson's. Effective treatment may be dependent on understanding the context of living with Parkinson's in Saudi Arabia, as culture and beliefs present challenges to healthcare and rehabilitation. There has been limited research on health practices within the SLT field in this country, suggesting a need for further research. An additional purpose of this study was to explore the influence of culture on how people experience and cope with Parkinson's in general. Specifically, it examined how a person living in Saudi Arabia who has Parkinson's experiences eating and drinking changes and how these changes impact his or her life as well as the lives of his or her carers and family.

1.2 Motivation and Importance

This study was inspired by my direct professional experiences as a Speech and Language Therapist working in Saudi Arabia with people with Parkinson's. Direct occupational experiences are often a starting point for research (Silverman, 2013) and can be an effective way to develop and adapt evidence-based practice in clinical settings. As a clinician, I worked with people with Parkinson's for more than seven years prior to my doctoral work, and I often dealt with communication and swallowing issues.

Developing a critical eye when it comes to new techniques has been a challenge among speech and language therapists in Saudi Arabia. There is a limited number of SLTs in the country, and the feelings of inexperience that many of us report, combined with the sense that we are behind other SLT services in 'developed' countries make us question our techniques. We often find ourselves applying what we have read exactly as our textbooks say.

Over time, I have come to recognise that there are factors that affect the way we apply both our assessments and our therapies, and that these factors need to be examined more closely in order to provide effective care for this population. Those who attend our clinic are not just people with Parkinson's, they are *Saudi* people with Parkinson's, which presents unique challenges associated with the culture.

We often see results that are different from what has been published in the studies and books we have read. For example, one situation polarised SLTs in our clinic: when we began to apply the Lee Silverman Voice Treatment (LSVT) programme (Fox *et al.*, 2012). This was something in which we had invested money and time to become fully certified to use with our Parkinson's patients. The unexpected results of applying this programme (very low compliance and attendance from our patients as well as far lower success rates and application at home than suggested in the literature) made us want to understand why we were not getting the same or similar results expected from our training. We were facing problems both in applying the programme and with the results of the programme that we had never read of or talked about with the LSVT global group who were responsible for the training. There were several explanations for the unexpected outcomes. It may be that the treatment is not appropriate for the people in this country, it may be that the people do not like or want the treatment. Further exploration of the issues that hinder Saudi patients benefitting from these treatment programmes was clearly needed.

As a speech and language therapist, I believed that I was providing the services that my patients needed and wanted. However, after years of working with the older population and specifically Parkinson's patients, I came to the conclusion that my patients were not actually following the recommended solutions I was providing. This, I interpreted, was a lack of acknowledgement of their say in the matter. Although I practise with the belief that the SLT and the patient are a team and the management programme should be planned with both their inputs, this was not the case. I found that my patients were not expressing their needs and were not accepting whatever programme I thought was suitable.

This led to another point, which was the compliance of the swallowing clinic patients. The patients who visited the clinic had very high no-show rates. I knew that what we were providing was not what the patients wanted but I did not know how to address this issue. I decided to design a study that examined the patients of this swallowing clinic and try to understand what can be done so that Saudi patients can benefit from the treatment programmes available.

To this end, I needed to understand how people from Saudi Arabia experience swallowing changes that are the result of their Parkinson's. It is possible that patient behaviours may be different from people in other countries. I also needed to explore the impact of these changes on both them and their families, and how they dealt with these changes in the context of Saudi culture and its limited medical services. Understanding the context of these symptoms will provide insight for the field of speech and language therapy.

The speech and language therapy field in Saudi Arabia is uniquely situated. In recent years, Saudi Arabia has experienced political, social, and economic changes that have resulted in fast modernisation of a traditionally tribal culture. It remains to be seen how the dramatic changes in Saudi Arabia's recent growth will affect the way Saudis view health services. Current health services in Saudi Arabia are based on research that is primarily on cultures with substantial differences from Saudi Arabia, which has implications for the appropriateness of the health services offered. Speech and language therapists in Saudi Arabia, as well as others in the health field, would benefit from research tools that would allow them to contribute to the development of research in the country. This would also allow them to contribute to the construction and development of the country's health services in a way that is sensitive to the cultural and religious beliefs of the patients. Although in Saudi Arabia hospitals are always encouraging staff to engage in research, staff workload is such that it prohibits them from conducting research. Once the demands of patient load per

clinician increase, any time allocated to research is usually the first to be sacrificed. In addition, the knowledge clinicians have in conducting strong research as well as the availability of researchers and resources to aid in this research process in Saudi Arabia are lacking. This is the reason I chose to attend Newcastle University to pursue a PhD. By learning to conduct research, I will bring these skills back to my home country of Saudi Arabia to contribute to programmes in health services.

1.3 Structure of the Thesis

This thesis is organised into seven chapters. Chapter one introduces the study, explains the motivation and importance for conducting this study, and describes the structure of the paper. Chapter two reviews the literature on issues related to Parkinson's, including diagnosis, management, and prevalence. It also includes a review of the literature on dysphagia, with an overview of normal swallowing, aetiology, the relationship between Parkinson's and dysphagia, and the impact of dysphagia on people with Parkinson's and their carers. It then provides an overview of the context of living in Saudi Arabia, including the social norms and customs around eating and drinking as well as how Muslims cope with changes due to health conditions. Chapter three presents the research question and study aims, and chapter four describes the methodology of the study. In part one of chapter four, the case is made for the chosen methods including philosophical assumptions, philosophy of the research, and the researcher's position. Part two of chapter four describes the study design followed by a detailed description of the data collection. It also includes a description of the participants, sampling, recruitment process, and data analysis. It concludes with a discussion on ethics and the ethical processes for this study.

In chapter five, the findings are presented. The chapter is organised to show how the focus group and the initial interviews informed subsequent interviews, making the data richer to better understand the experiences of this population. In chapter six, the findings of the study are considered in light of the existing literature. This chapter includes reflections on the findings in relation to eating and drinking changes as well as in relation to the culture of Saudi Arabia. It also provides a discussion of the implications of this study on both clinical practice and research in Saudi Arabia in general. Chapter seven includes conclusions from the study.

Chapter 2. Literature Review

This chapter reviews the literature relevant to the study. It is divided into sections on Parkinson's, dysphagia, and Saudi Arabia. The first part describes Parkinson's disease and its symptoms, global prevalence, and general issues in management. It also reviews the literature on the impact of Parkinson's on both patients and their families. The second part reviews dysphagia and its relationship to Parkinson's, including the impact of dysphagia on people with Parkinson's. This section identifies research gaps in the knowledge base on Parkinson's. The third part of the chapter reviews research on the influence of culture on coping with illness and describes the culture in which the current study was conducted. Specifically, it describes the features of the culture of Saudi Arabia that are relevant to the study, especially the customs and social norms related to eating and drinking.

2.1 Parkinson's

2.1.1 An Overview

Parkinson's is a chronic, progressive, neurodegenerative disorder with three cardinal motor symptoms: tremors, rigidity, and a slowed ability to start and continue movements (bradykinesia). It was named after James Parkinson, the 19th-century London surgeon and chemist who first described most of its symptoms (Lewis, 2012). The aetiology (neuropathology) of Parkinson's has been attributed to the reduction of neurons in the substantia nigra nucleus of the basal ganglia, resulting in (a) a reduction of dopamine, a chemical that works as a transmitter to regulate body movements, and (b) the development of Lewy bodies, which represent abnormal collections of proteins.

The main cause of Parkinson's is still unknown, but there is evidence that, at least in a substantial proportion of patients, it may be due to genetic influences or exposure to certain viruses or toxic substances (Das et al., 2011). Some research has suggested that both environmental and genetic factors contribute to the triggering of PD (Warner et al., 2003; Schapira and Jenner, 2011; Schapira, 2011).

In addition to the main (motor) symptoms, people with PD also experience a range of nonmotor changes, including cognitive changes, mood depression, pain and sleep

disturbances (Postuma *et al.*, 2015; Marras and Chaudhuri, 2016) . Among the many functions that can be disturbed by these motor and nonmotor changes are speech, use of the voice, eating and drinking. Changes to both the centrally patterned and volitional aspects of swallowing can lead to dysphagia (impairment of swallowing), and these are covered below.

2.1.2 Prevalence

Studying the prevalence of disease is important for planning and developing health services. Parkinson's is found throughout the world, in all ethnic groups, regardless of sex. The disease usually occurs only in adults and is very rare in children. In the United Kingdom, the Parkinson's prevalence rate in 2009 was calculated at 27 per 10,000 people, which is equivalent to 126,893 cases when scaled up to the total UK population (Parkinson's UK, 2009). In 2014 in Canada, 0.2% of adults in private households had Parkinson's (Wong *et al.*, 2014). The prevalence of Parkinson's increases with age from 41 per 100,000 in 40-year-olds to 1,087 per 100,000 in 79-year-olds, and 1,908 in over 80-year-olds (Pringsheim *et al.*, 2014).

Worldwide, the disease has an annual incidence rate between 4.5 and 19 per 100,000 people (World Health, 2006). The wide range of the incidence rate is due to the fact that the reporting of the disease differs from one country to another. In 2014, Pringsheim *et al.* completed a systematic review of the global prevalence of Parkinson's with a meta-analysis of published, door-to-door and population-based random sampling assessments of the condition performed between 1985 and 2010 (Pringsheim *et al.*, 2014). The study found wide differences in the prevalence of Parkinson's across regions, attributing them to methodological differences.

Few studies have examined the prevalence of Parkinson's in the Arab-speaking world. The Arab world has over 365 million people in 22 countries, but only a few of these countries have produced research on the prevalence of Parkinson's. Benamer *et al.*, in 2008, conducted a systematic review of Parkinson's research in the Arab region and found that the prevalence of Parkinson's among Arabs (27 to 43 per 100,000 persons) is higher than in Sub-Saharan Africa and China but lower than in developing countries. This review covered the period from 1986 to 2007. Only 29 reports were identified, and only one study originated in Saudi Arabia (Benamer *et al.*, 2008), but the results suggest high incidence and variations of prevalence between regions. The most recent study of Parkinson's prevalence in the Arab world was conducted in 2010 in Wadi Ara in Israel. The prevalence of Parkinson's was 43.24/100,000

overall and 477.32/100,000 in the above-65 group (Masalha et al., 2010). The numbers from these studies may not be comparable as they used different methodologies to collect their data and there was a time gap of 17 years. Nevertheless, these studies indicate a large gap in Parkinson's prevalence studies in the Arab world.

The single study on Parkinson's prevalence in Saudi Arabia was conducted in 1993 in Althughbah (a district of the Eastern Province with a population of 192,000). The study involved a door-to-door pretested questionnaire leading to a neurological evaluation of those who gave abnormal responses. A total of 23,227 Saudis were tested. The overall prevalence ratio of all forms of neurological disease was 131/1,000, with Parkinson's being rated as uncommon (a prevalence ratio of 0.27, which is 2.7/1000). It is important to note that of those screened, only 1.5% were over the age of 60 and more than 42% were under the age of 10 (Al Rajeh et al., 1993). The low number of older people screened may be due to Saudi Arabia's having a relatively young population. Based on the 2010 census, 32% of the Saudi population is younger than 15, and only 2.8% is above the age of 65 (UNICEF, 2013). Consequently, most of the country's health services have shifted to a focus on paediatric services and paediatric studies, and very few resources are allocated to senior care studies. Research on Parkinson's and similar neurological conditions is needed, especially now, because life expectancy in Saudi Arabia has risen. It is reported that life expectancy in 2012 was 73.8 years, exceeding the global average by 3.8 years (Ministry of Health, 2012).

2.1.3 Symptoms and Diagnosis

The motor symptoms of Parkinson's are; bradykinesia, tremor at rest, and rigidity, leading to postural instability and gait disturbance (Postuma *et al.*, 2015). Bradykinesia is a slowness of body movement that involves a delay in initiating movement as well as decrease in the speed of repetitive movements. Initially this may manifest itself for instance in asymmetrical reduced arm swing when walking, where one arm swings less than the other, but later progresses to no swinging arms at all (Sánchez-Ferro *et al.*, 2016). Tremor at rest or when holding a particular posture is the most recognisable symptom in a fair proportion of people with Parkinson's, initially mostly unilateral. It involves a rhythmic oscillation of a body part, typically affecting the distal part of the extremities, but it can also affect the lips, chin, and jaw as well as the legs (Jankovic, 2008; Schapira, 2010). Rigidity includes stiffness of muscles and is evident in passive movements of the limbs, on flexion or extension. The

increased rigidity and loss of postural reflexes associated with late stages of Parkinson's result in the development of postural instability.

These cardinal motor symptoms of Parkinson's can lead to shuffling gait, freezing of gait (or other activities – where in the middle of an action the person is unable to move on), and dystonic postures (Thomas, 2014). A feature of Parkinson's is the presence of disabling dyskinesias, which may be associated with pharmacological interventions. Motor changes also impact on both the centrally patterned and volitional aspects of swallowing, which can lead to dysphagia (impairment of swallowing).

The motor symptoms outlined above are the principal symptoms of Parkinson's, but the disease also has non-motor symptoms. People with Parkinson's complain of some of the symptoms listed in table 1, the presence and degree of which vary from one person to another.

Table 1 Non-motor Symptoms of Parkinson's

Neuropsychiatric symptoms	Anxiety Apathy Cognitive issues Compulsive and repetitive behaviour [usually drug induced] Confusion [may be drug induced] Delirium [may be drug induced] Dementia Depression Hallucinations, illusions, delusions Panic attacks
Sleep disorders	Excessive daytime somnolence Insomnia Rapid eye movement [REM] sleep behaviour disorder Restless legs and periodic limb movements Sleep apnoea or disordered breathing

	Vivid dreaming
Autonomic symptoms	<p>Bladder dysfunction</p> <p>Coat-hanger pain</p> <p>Dry eyes [xerostomia]</p> <p>Erectile dysfunction</p> <p>Falls related to orthostatic hypotension</p> <p>Hypersexuality [usually drug induced]</p> <p>Nocturia</p> <p>Orthostatic hypotension</p> <p>Sexual dysfunction</p> <p>Sweating</p> <p>Urgency</p> <p>Urinary Frequency</p>
Alimentary canal [overlap with autonomic symptoms]	<p>Ageusia</p> <p>Constipation</p> <p>Dribbling of saliva</p> <p>Dysphagia and choking</p> <p>Faecal incontinence</p> <p>Incomplete voiding of bowel</p> <p>Nausea</p> <p>Reflux</p>
Sensory symptoms	<p>Olfactory disturbance</p> <p>Pain</p> <p>Paraesthesia</p>
Miscellaneous symptoms	<p>Fatigue</p> <p>Diplopia (double vision)</p>

	Blurred vision
	Weight loss and Weight gain [usually drug induced]

Table adapted from (Chaudhuri *et al.*, 2012).

Some of these symptoms appear in the early stages of Parkinson's. For example, constipation and compromised smell and taste have been reported in patients prior to diagnosis (Breen and Drutyte, 2013). Others occur at late stages of the disease and may be attributable to or aggravated by Parkinson's medication (Pandya *et al.*, 2008). Recent research suggest that non-motor symptoms might be caused by problems in non-dopamine-secretion regions (Chaudhuri *et al.*, 2012).

Diagnosis

There are no specific tests or tools for the diagnosis of Parkinson's. When General Practitioners suspect Parkinson's, they typically refer patients to a specialists, most likely a neurologist or geriatrician. Diagnosis is based on the presence of two of the cardinal symptoms mentioned above (Gelb *et al.*, 1999; Bhidayasiri and Reichmann, 2013; Rizzo *et al.*, 2016) and the exclusion of other disorders that might have caused them. The most widely used diagnostic approach is the United Kingdom Parkinson Disease Society Brain Bank set of clinical diagnostic criteria (Hughes *et al.*, 1992; Postuma *et al.*, 2015). It requires the existence of two of the motor symptoms, one of which must be bradykinesia (Bhidayasiri and Reichmann, 2013).

Part of the medical management process is that doctors attempt to rate the progress of the symptoms using a number of tools (Martínez-Martín and Cubo, 2007; Goetz *et al.*, 2008; Grill *et al.*, 2011; Rodríguez-Violante and Cervantes-Arriaga, 2014). One of the oldest tools still in use is the Hoehn and Yahr scale, which is a method of identifying the overall motor stage of the disease ('0' is the mildest stage, in which the symptoms are unilateral and there is little or no functional disability, and '5' is the most advanced stage, in which the symptoms are severe and the person is bedridden or wheelchair bound) (Hoehn and Yahr, 1967; Goetz *et al.*, 2004; Zhao *et al.*, 2010). The Hoehn and Yahr's scale is a universally accepted scale and is a recommended scale by the Movement Disorders Society Task Force (Sampaio *et al.*, 2012). Another scale used is the Unified Parkinson's Disease Rating Scale (UPDRS) which was designed to provide an effective means to rate the impairments and disabilities of people with Parkinson's and their longitudinal progression (Fahn, 1987). It was revised and updated by Goetz *et al.* (2008).

2.1.4 Management

Although Parkinson's is currently incurable, people may live several decades with Parkinson's (Hobson *et al.*, 2010). Its symptoms can be managed by pharmacological therapies, surgical interventions, or rehabilitation techniques. Medications are typically used to mitigate the symptoms of Parkinson's to improve the patient's quality of life, or reduce the side effects of other Parkinson's medication. These involve the use of chemicals that are converted to dopamine in the brain with some medications boosting the activity of dopamine (i.e., a dopamine agent) and some replacing the lost dopamine (i.e., Levodopa) (Thomas, 2014) and others inhibiting the further breakdown of dopamine. Many of these medications have strong side effects such that other medications are necessary to manage these effects.

The long-term use of many of these medications in this population is associated with loss of effects and complications, including disabling dyskinesias and possible impulsive behaviours. Hence pharmacological management is an ongoing and complex task. Surgical interventions are now a management option for some people with Parkinson's, particularly in view of recent advances in neurosurgery and neuroimaging (De Chazeron *et al.*, 2016). Types of surgical interventions include deep brain stimulation, ablative procedures, and restorative procedures (Merola *et al.*, 2016). Deep brain stimulation, the most common surgery, involves electrically stimulating various key areas in the basal ganglia. This surgical option has proved successful in controlling some of the motor symptoms and non-motor symptoms (Ashkan *et al.*, 2013) of Parkinson's for selected patients (Fox *et al.*, 2011). Deep brain stimulation may have a deleterious effect on speech (Little *et al.*, 2016), though its impact on swallowing is neutral or positive (Kulneff *et al.*, 2013).

The motor and non-motor symptoms of Parkinson's can also be managed through behavioural rehabilitation. Physical therapy, occupational therapy, and speech and language therapy (SLT) are the main disciplines of rehabilitation used to treat Parkinson's. Nutritionists/dietiticians and social workers may also be involved. These different disciplines of allied health services for people with Parkinson's have been examined in the West, and their effectiveness has been documented and evaluated by many studies (Gage and Storey, 2004; Nijkrake *et al.*, 2009; Ransmayr, 2011; Herd *et al.*, 2012; Manor *et al.*, 2013). Studies of rehabilitation programmes for Parkinson's have shown that certain aspects of patients' lives improve in response to these programmes, but there is still a lack of robust evidence regarding the effectiveness of Parkinson's rehabilitation. Most studies report their results in terms of

statistical significance but lack explanations of clinical significance (Gage and Storey, 2004; Tomlinson *et al.*, 2012).

Speech and voice management

Difficulties with speech and voice are also challenges for people with Parkinson's. The chief speech and voice changes are usually slurred or mumbled speech, reduced voice intensity, breathy or hoarse voice as well as lack of self-monitoring of voice intensity. Other communication issues are lack of facial expressions and difficulty finding words (Ramig *et al.*, 2011). In SLT rehabilitation services, the Lee Silverman Voice Treatment (LSVT) approach is one technique that has proved a successful management option for some people with voice difficulties, showing improvement of voice and overall speech intelligibility (Sapir *et al.*, 2011; Wight and Miller, 2015). The treatment is an intensive programme provided by a SLT with a certification of training by the, for profit, LSVT Global group. The programme focuses on voice-loudness training, emphasising maximum effort and sensory feedback through an intensive treatment schedule that lasts four consecutive weeks. Each week consists of four treatment sessions, and each session is 50 to 60 minutes long (Spielman *et al.*, 2007).

Studies on the effectiveness of LSVT and other rehabilitation methods (Lowit *et al.*, 2010) are promising, but more research is indicated. One study that investigated the effect of LSVT on dysphagia found short-term but no long-term benefits for dysphagia (El Sharkawi *et al.*, 2002). Another example of a treatment programme for dysphagia secondary to Parkinson's that has been examined, is a skill training for swallowing rehabilitation programme, called Intensive Therapeutic Manoeuvre Oropharyngeal Programme (Felix *et al.*, 2008); . The measurements of success for these programmes were usually recorded immediately after the programme ended and there were no measurements for long-term effects. The lack of long-term effects in one study and the lack of follow-up studies for findings of short-term effects, coupled with the fact that these programmes require intensive in-session training, which usually take one or two sessions a week for up to 12 weeks, make rehabilitation a challenging option.

2.2 Issues Associated with Parkinson's

2.2.1 Dysphagia

Dysphagia is one of the more common symptoms of Parkinson's (Troche et al., 2008; Hammer et al., 2013). 'Dysphagia' is the medical term for any impairment or difficulty in the swallowing process. It is a recognised symptom of many disorders, and has been found to be one of the earliest symptoms of Parkinson's (Potulska et al., 2003). It is typically classified as a symptom of a disease by the ICD-10 (the International Statistical Classification of Diseases and Related Health Problems), but can also be classified as a condition or disorder in itself.

Dysphagia seems to worsen with age. A study by Cereda et al. (2014) found that dysphagia in people with Parkinson's is associated with disease duration, age, and presence of dementia. This was supported by a study that found that those in the early stages of Parkinson's had significantly fewer swallowing symptoms than those in more advanced stages and that cough rate (a mechanism that protects the airway) decreases as the disease progresses (Silverman et al., 2016). Many people with Parkinson's experience changes in their swallowing even before they complain of dysphagia (Ali et al., 1996; Miller et al., 2009; Bayés-Rusiñol et al., 2011).

Studies have reported variation in the prevalence of dysphagia in people with Parkinson's but agree that the rates are high. In one study of people with Parkinson's, as many as 90% reported developing dysphagia during the course of the disease (Shimon Sapir, 2008). Using meta-analysis to estimate the prevalence of dysphagia in Parkinson's, Kalf et al. (2011) found that dysphagia is prevalent in at least 1 out of 3 people with Parkinson's and that people with Parkinson's are 3 times more likely to have swallowing disorders than healthy members of a control group. The differences in these studies could be attributed to the fact that the meta-analysis included only people with Parkinson's who are living in the community and excluded those with Parkinson's that are hospitalized or in nursing homes. Kalf et al. (2011) also found that dysphagia occurs in nearly 100% of people with advanced stage Parkinson's. Takizawa et al. (2016) conducted a systematic review of the literature on the prevalence of dysphagia in Parkinson's and other neurological disorders and found that oropharyngeal dysphagia affects between 11% and 60% of people with Parkinson's (Takizawa *et al.*, 2016). They explain this wide range in prevalence as a function of the variety of methods used to detect dysphagia. Noble et al. (2015) support this as in their study they found that in their sample of people with Parkinson's with dysphagia some were unaware that they had a problem (Noble *et al.*, 2015). The mixed results further support the need for more accurate data in future studies of Parkinson's.

It is important to review the details associated with the swallowing process to understand how the process is disturbed in dysphagia. Swallowing is the mechanism by which food is transferred from the oral cavity to the stomach during the eating process. It is a complex sensorimotor behaviour involving the coordinated bilateral control of the musculature located around the mouth and at the tongue, larynx, pharynx, and oesophagus (Ertekin and Aydogdu, 2003; Koidou *et al.*, 2013). Together, the brain stem, basal ganglia, cortex, and other subcortical structures form the neural networks that control the swallowing function (Dodds *et al.*, 1990; Ekberg, 2012). These neural networks are normally triggered by sensory input (Lowell *et al.*, 2008). Although much of the movement associated with swallowing is triggered automatically by reflex reactions, there is a significant voluntary cognitive-motor component involved in chewing and preparing a bolus for swallowing.

The process of swallowing has three phases. In the oral phase, the food is chewed and converted into a bolus. It starts when the food passes the lips and begins to be masticated and mixed with saliva to reduce the food to a size that can be swallowed via both the pharynx and oesophagus (Shaker *et al.*, 2013). This stage involves the coordination of the muscles and neurons that control the mandible, hyoid bone, and tongue. It also involves sensory feedback, and the size and consistency of the bolus will affect the duration and amplitude of this stage (Jean, 2001). In the pharyngeal phase, the material that needs to be swallowed has been formed into a bolus, and this bolus has to pass through the pharynx to reach the oesophagus. The pharynx's main function is to serve as a passage for air, but during eating and drinking, the central nervous system gives it another function, which is to pass the bolus into the oesophagus while protecting the airway (Shaker *et al.*, 2013).

This phase starts with the elevation of the anterior hyoid bone; the effect of its elevation on the angle of the larynx protects the airway. The tongue moves the bolus backward towards the pharynx. To protect the airway, the epiglottis cartilage closes and the true and false vocal cords abduct during bolus transport from pharynx to oesophagus (Cichero and Murdoch, 2006). Next, the bolus enters the oesophagus, which is achieved by the crico-pharyngeal muscle pushing the bolus towards the upper oesophageal sphincter. This sphincter is typically in a closed position but relaxes to allow the bolus to enter. Oesophageal peristalsis, the wavelike contractions by which the bolus is moved through the oesophagus, allows it to reach the lower oesophageal sphincter. Once the bolus passes this sphincter and enters the stomach, the swallowing process is complete (Shaker *et al.*, 2013).

Studies of swallowing have shown that all phases of swallowing, from chewing and oral formation of the bolus, to tongue movement and the pharyngeal and oesophageal stages of swallowing, are impacted by Parkinson's (Ertekin *et al.*, 2002; Blumin *et al.*, 2004; Suntrup *et al.*, 2013). The underlying pathology of the relationship between dysphagia and Parkinson's is somewhat unclear. Parkinson's is a multi-layered disease, and dysphagia can be attributed to one or all of its layers.

2.2.2 *The multi-layered nature of Parkinson's*

At the neural level, studies show that dopamine reduction may cause both Parkinson's and (some of) its dysphagia symptoms. Basal ganglia play an important role in controlling swallowing (Leopold and Daniels, 2010), and they contain the substantia nigra, where dopamine reduction occurs in people with Parkinson's (Pfeiffer and Bodis-Wollner, 2013). Studies have shown improvement in swallowing abilities in people with Parkinson's after treatment with a drug to increase dopamine in the brain (Sutton, 2013; Warnecke *et al.*, 2016).

Some researchers have suggested that Parkinson's symptoms, like rigidity and bradykinesia, underlie the abnormalities of swallowing in people with Parkinson's (Robbins *et al.*, 1986; Kim *et al.*, 2015). In a study examining the tongue control of people with mild to moderate Parkinson's, researchers found differences in tongue movement between people with Parkinson's and healthy controls when presented with liquids of different thickness or consistency (Van Lieshout *et al.*, 2011). (The results of that study should be interpreted with caution as some of the participants were on dopamine therapy and others were not, and the differences in tongue movement between the two groups were not examined.) Another study showed that repetitive lingual pumping and unstable intraoral organisation of the bolus might be associated with bradykinesia, which results in food entering the airway in people with Parkinson's (Argolo *et al.*, 2015).

One of the non-motor syndromes of Parkinson's is drooling, which was recently found to be associated with dysphagia (Nóbrega *et al.*, 2008). In a review of the literature on Parkinson's-related drooling, Chou *et al.* found evidence suggesting that drooling in Parkinson's may be due to infrequent swallowing as opposed to excessive production of saliva (Chou *et al.*, 2007). In a recent study, Ellerston *et al.* (2016) measured swallowing changes in people with Parkinson's and concluded that pharyngeal constriction and airway closure, both of which are important swallowing mechanisms for airway protection, are compromised in people with Parkinson's (Ellerston *et al.*, 2016). A common abnormality that speech and language therapists observe in people with Parkinson's is the leakage of fluids or food from the oral

cavity posteriorly into the pharynx, potentially reaching the airway and causing unsafe swallowing.

Because people with Parkinson's experience dysphagia, they are at risk for other health issues. They often avoid certain foods, especially solids, and as a result, are more vulnerable to weight loss and nutritional intake issues than their healthy counterparts (Lorefält et al., 2006b). Some serious health issues that are often associated with dysphagia are malnutrition and dehydration (Barichella et al., 2009; Barichella et al., 2013), as is extreme weight loss (Lorefält et al., 2006b). Studies have also linked aspiration pneumonia to Parkinson's (Akbar et al., 2015) and to dysphagia in people with Parkinson's (Monteiro *et al.*, 2014). Parkinson's patients who report swallowing difficulties have been found to be at higher risk of developing aspiration pneumonia (Moti et al., 2016). Aspiration pneumonia stemming from dysphagia has been cited as a leading cause of death in people with Parkinson's (Fall et al., 2003; Hely et al., 2008), as well as bronchial pneumonia caused by choking (Wang et al., 2002).

Fortunately, early dysphagia screening and intensive oral hygiene programmes may be able to reduce the risk of pneumonia. There is research that links swallowing disorders, oral health, and the likelihood of pneumonia (Sørensen et al., 2013) that shows promise.

Diagnosing and reporting of dysphagia are challenging because reports from patients, carers, and clinicians do not always align. For example, Martino et al. identified a difference in the way these three parties perceived the relationship between dysphagia and its consequences. Clinicians have a tendency to isolate the consequences of pulmonary, nutritional, and psychological impairment and deal with each individually, while carers described a feedback relationship between these consequences (Martino *et al.*, 2010). Patients' perception however was more complex and dealt mostly with the psychological domain. McKinlay *et al.* (2008) similarly found low levels of agreement between reports from people with Parkinson's and their caregivers with respect to quality of life. This implies that the two methods of assessment of quality of life cannot be considered interchangeable and therefore both reports from patients and carers are needed. This also suggests a need for more qualitative studies to examine contrasting viewpoints on the issues associated dysphagia, so that clinicians can identify the presence of these issues and address them according to both the patients' and carers' needs.

Similarly, individuals with dysphagia are not the most accurate reporters with regard to identifying dysphagia. Miller et al. (2009) found that self-reported swallowing difficulties are not a reliable indicator of swallowing ability. A meta-analysis (Kalf *et al.*, 2011) showed that

subjective measures of dysphagia indicate a much lower incidence than objective measures. And Noble et al. (2015) reported that some of their sample of people with Parkinson's were unaware of their swallowing problems despite reduced swallowing efficiencies, requiring more specific questions to accurately assess difficulties. The implication of these studies is that clinicians should not rely solely on objective reports of swallowing issues and should ask patients about their eating lives in general, including meals and social events that involve eating to accurately assess swallowing difficulties.

2.2.3 The psychosocial impact of dysphagia and Parkinson's

Although much research has examined the impact of Parkinson's on physical health, other studies have investigated its psychosocial impact. The World Health Organisation supported this type of research in its development of the International Classification of Functioning, Disability, and Health (ICF) framework. This framework uses a biopsychosocial model of disability in which a diagnosis alone is insufficient to determine a patient's quality of life. It calls for the need for information on both function and disability to develop an international standard to describe, measure, and treat illness (World Health, 2001). The biopsychosocial model involves looking at health, not only in terms of physical illness, but also in terms of a range of biological, psychological, and social factors that contribute to the health and well-being of the patient (Alonso, 2004). According to this model, the dysphagic symptoms of people with Parkinson's should be understood in the context of the entire eating process.

The food-related habits of people with Parkinson's change over the course of the disease (Lorefält et al., 2006a), with difficulty eating as the most commonly reported physical symptom (Goy et al., 2007). Ney et al. argued that safe swallowing is a basic human need and pleasure (Ney *et al.*, 2009). It has also been found that people with Parkinson's often prefer not to eat in public due to fear of choking and embarrassment about drooling and the slow pace at which they eat (Rosenbek and Jones, 2009). In another study, people with Parkinson's expressed that the challenges of eating with other people affect their self-esteem, and they experienced a decreased pleasure in enjoying meals that sometimes resulted in social withdrawal (Westergren *et al.*, 2016). A study by Soleimani (2014) that aimed at showing the impact of Parkinson's on the social interactions of the person with Parkinson's revealed that people with Parkinson's shrink from social activities and seclude themselves. The study employed an interview method and the majority of the people with Parkinson's that were interviewed expressed that Parkinson's has affected their social lives in many ways, including social activities. The interviews of this study show that the people with Parkinson's feeling of

shame and embarrassment leads to their concealing themselves from social activities and results in seclusion (Soleimani et al., 2014).

To understand why this occurs, studies in the last few years have examined dysphagia in a variety of neurological diseases, and the results of these studies can help in understanding what people with Parkinson's might experience. The use of qualitative methods has been particularly useful in highlighting issues and processes that are affected because it allows for a phenomenological exploration.

A study of eating difficulties in stroke patients found that patients struggle with manipulating food in the mouth, resulting in fear regarding the possibility of choking while eating (Jacobsson et al., 2000). In stroke research, studies have found that aspects of eating like the ability to sit and eat, managing food on the plate, and manipulating food in the mouth affect adequate food consumption as well as swallowing (Medin et al., 2012). Stroke patients have also reported feelings of oral discomfort, and noted how the immobility of their hands and arms made them feel uncertain about body control (Jacobsson et al., 2000). As a result, they felt ashamed of their appearance when food and liquids leaked from their mouth during eating. Negative feelings associated with suddenly being dependent on others for eating and feelings of embarrassment while eating were also reported in these studies (Jacobsson et al., 2000; Medin et al., 2010). The experience of eating difficulties can lead to loss of social life with an ongoing life adjustment process due to the physical and psychosocial impact of these eating difficulties.

Interactions with other people seem to play an important role in adjustment to eating difficulties (Klinke et al., 2014). A study of people in palliative homecare with different diagnoses found that eating difficulties influence relationships with family members and social interactions (Wallin et al., 2015). In a study in which family members of people with eating problems due to stroke and traumatic brain injuries were interviewed, family members reported that the unpleasant sounds from the oral cavity and pharynx, and the saliva leaking from the person with Parkinson's mouth, made them lose their appetite and leave the dinner table (Johansson and Johansson, 2009). This as well as feelings of embarrassment may explain why people with Parkinson's tend to seclude themselves.

Recent research has described the impact of non-motor symptoms on people with Parkinson's. For example, the impairment of daily living activities has been found to have a negative effect on the quality of life of people with Parkinson's (Soh et al., 2011), and depression is one of the most common non-motor symptoms of Parkinson's (Brown et al.,

2011; Duncan et al., 2014), being reported in 20% to 40% of Parkinson's patients, a rate that is much higher than that associated with the general population (Lieberman, 2006). This finding was explained in a study on the relationship between quality of life and swallowing in patients with Parkinson's, which suggested an association between swallowing, social function, and depression (Plowman-Prine et al., 2009). In people with Parkinson's, dysphagia exerts a negative effect not only on the acts of chewing and swallowing, but also on other activities related to eating, such as shopping for and preparing meals (Lorefält et al., 2006a; Miller et al., 2006) as well as eating in a socially acceptable manner (Miller *et al.*, 2011).

The context of eating is also an important factor to consider when thinking about changes in the social lives of people with Parkinson's. The shift from a meal that is shared, social, and pleasant to an activity that is filled with discomfort, isolation, and embarrassment is a large change in its own right but also may influence quality of life in general. In a study that evaluated the impact of dysphagia on quality of life in healthy aging people and in people with Parkinson's (Leow *et al.*, 2010b), researchers found that quality of life in people with Parkinson's was significantly reduced by dysphagia. The main issues reported were difficulties in selecting food textures that are safe to eat and finding foods that are both enjoyable and safe to eat. Additionally, the fear of socialising is greater and a decreased desire to eat is much more common among people with Parkinson's than among healthy aging individuals.

These issues have also been examined in the context of working with older patients with various issues related to eating. The effects of the cultural and social aspects of mealtime on nutrition itself have typically been ignored by researchers in the past (Fjellström, 2004). Recent studies have shown that social settings are an important determinant in the quality of one's diet (Holmes and Roberts, 2011), and there is evidence that the presence of others and the eating behaviours of others during a meal influence the food intake of the person (Vartanian et al., 2008). In addition, it has been found that living arrangements and social organization have an impact on older people's mealtimes and nutritional intake (Sydner and Fjellstrom, 2005). Aselage and Amella propose that mealtimes encompass more than a physical act and propose a conceptual model of mealtime difficulties that consider environmental, social, cultural, and contextual implications of nutritional intake (Aselage and Amella, 2010).

The changes in eating and drinking are part of a shift to a new stage or identity in a person's life. The eating and drinking changes in people with Parkinson's seem to require a redefinition

of what constitutes a normal life. One study on people with Parkinson's found that successful living means maintaining a usual state of health or a readjusted state of health (Kang and Ellis-Hill, 2015), reinforcing the idea that with changes in eating and social norms also comes changes in norms about daily life.

Researchers in Spain explored the significance of mealtimes in a nursing home and found that the mealtime is a point of reference around which all the day's activities are organized (Palacios-Ceña et al., 2013). Another study compared the clinical setting of dysphagia assessment with the more natural setting of eating at home and highlighted the marked differences. The food as well as the physical and social environment of the clinic were not appealing, pleasurable experiences in contrast to the more natural and social meal setting where the food is appealing and familiar to the person, with conversation happening while the person is eating and drinking (Threats, 2007). The loss of this experience may be a factor in understanding the depression and anxiety that accompany Parkinson's.

In addition to considering the psychosocial impact of Parkinson's-related eating and drinking changes on the person with Parkinson's, several studies have investigated the psychosocial impact on caregivers of people with Parkinson's. Studies have shown that caring for a person with Parkinson's is associated with a high level of caregiver burden with a significant impact on caregivers' physical and mental health (Schrag et al., 2006). Caregivers report high levels of stress (McRae et al., 1999) and that the presence of dysphagia has a negative impact on their social and family lives, with caregivers expressing frustration, anger, and stress over meal-preparation duties (Nund et al., 2014). In a study that examined how swallowing difficulties influence daily life, of all the dimensions within the scale, burden of care represented the most significant difference between healthy adults and people with Parkinson's (Leow *et al.*, 2010c).

Although dysphagia and Parkinson's have been studied from a considerable number of viewpoints in the United Kingdom and in the United States (Stroudley and Walsh, 1991; Kurihara *et al.*, 1993; McHorney *et al.*, 2000; Leow *et al.*, 2010b), more research is needed, as almost all the articles cited in the present study identified gaps in knowledge and made recommendations for further research.

To address the issues and difficulties that people with Parkinson's experience during their meals, current research suggests a need to look beyond the swallowing process and the mechanical act of eating itself. Many issues can cause people with Parkinson's to be challenged during meals because Parkinson's affects the functions of the upper extremities

(e.g., fine motor dexterity affects the use of utensils), resulting in increased difficulties with acts of daily living and self-care and requiring assistance from carers. As the disease is progressive, these symptoms increase and subsequently increasingly restrict participation in activities for both the person with Parkinson's and their carer (Quinn et al., 2013), which has multiple psychosocial implications for the quality of life of people with Parkinson's and their carers.

2.3 The Cultural Context of Health Research

The definitions of health and illness vary between different cultures and societies; health is a multidimensional concept that involves physical as well as mental and social health (Helman, 2007). According to the Health Belief Model (HBM)(Hochbaum *et al.*, 1952), health behaviours are a product of the attitudes and beliefs of individuals (Becker and Rosenstock, 1984), and these attitudes and beliefs are influenced by both external and internal factors. A person's likelihood of participating in a health promoting behaviour is based on his understanding of the disease and the risk of its consequences, as well as his or her fundamental beliefs. The cultural context in which any health issue is situated is also an important aspect of understanding health behaviours, as the culture of the patient and his/her carer have an impact on their beliefs about health and illness.

The construct of culture is a set of ideas, beliefs, and rules that are practised by members of a group in their daily lives. These rules direct the members of the group on how to view the world, how to behave in it, and how to experience it (Helman, 2007). The transmission of culture is through interactions within and between generations with the practise of routines, traditions, dialogue, and artefacts (Wajman *et al.*, 2015). Another way of thinking about culture is that it is a "lens" through which a person perceives the world he lives in as well as how he interprets it. One of the features of this lens is that it provides a way to categorise, label, and make meaning (Helman, 2007). However other factors also influence health-related beliefs and behaviours including the age, gender, education, occupation, and unemployment but are still a product of the culture in which they occur (Helman, 2007). Incorporating culture into research on health and human development may explain pathways for understanding attitudes and behaviour and how they can change (Ajrouch, 2015).

Recent research on the relationship between culture and health concepts has shown that culture has a noticeable impact on health concepts, which in turn affect health practices (Levesque and Li, 2014). In a Canadian study of 60 participants from three cultural groups,

there were differences between groups on the definition of physical health, developmental health, spiritual health, and interdependence. The study suggested considering a cultural concept of how people *practise* health, including how they manage stress, what a healthy lifestyle looks like, and the individual and collectivist differences in families. For example, one of the groups defined health as a function of their family, community, and environment, while others focused more on individual health (Levesque and Li, 2014). The Western medical view of health is more individualised so more research is needed on collectivist perspectives on health and how health treatments can be adapted to be more culturally relevant.

Culture is an important element to include in research that is explorative and examines people's accounts of an experience that happens within cultural traditions. Eating and drinking are governed by the social norms and traditions that each culture has. Studies have looked at how families share meals and at their behaviours during meals and found that the family meal and all the behaviours of the members of the family represent the macro understanding of the cultural rules that govern the family (Belk et al., 2012). No studies have yet explored the mealtime behaviours of extended families in collectivist cultures such as Saudi Arabia, where the extended family is part of the daily or weekly meals. In addition, no studies have examined the mealtime behaviours of groups that are gender segregated during meals. In order to understand the influence that eating and drinking have on people with Parkinson's in Saudi Arabia as well as their health behaviours, it is important to consider the culture and belief systems in the country.

2.4 Saudi Arabia

The Kingdom of Saudi Arabia is one of the largest countries of the Arab world. Located within the Arabic peninsula, in the southwest of Asia, it occupies a central location in the Middle East. In the 2012 census, the total population was 28,287,900 (UNICEF, 2013). The country is the world's largest oil producer, and oil is the main source of its income. A striking characteristic of the population of Saudi Arabia is the large number of people under the age of 20. In 2005, people under 20 formed 49.3% of the total population; 2.73% of the population is over 65 (UNICEF, 2013). Life expectancy for 2012 was 73.8 years, exceeding the regional average by 5.8 years and the global average by 3.8 years.

As a young nation (founded in 1932), Saudi Arabia is a developing country. The population consists of Arabic tribes (clans that originated in the Arabic peninsula). Most of its population

was formerly nomadic (people who live by traveling from one place to another without a permanent residence), but with the development of the country and its vast economic growth, most of the population is now settled. The rapid development of the country has led to a heavy dependency on foreign workers (according to the April 2011 census: 18,707,576 Saudi nationals and 8,429,401 non-nationals), and this has resulted in high rates of unemployment (Ministry of Health, 2012).

Saudi Arabia is divided into 13 administrative regions (see figure 1), each with its own capital city, but culturally the people of the country are associated with five distinct regions: the Central region (Najid and the surrounding areas), the Western region (the part of the country that borders the Red Sea and contains Hijaz, the two holy cities, and Jeddah, the second largest city in the country), the Eastern region (which overlooks the Arabian Gulf and contains the country's oil reserves), the Southern region (which borders Yemen, contains the Asir Mountains, and is the greenest part of Saudi Arabia, which is predominantly a desert), and finally the Northern region (which borders Jordan, Iraq and Kuwait).



Figure 1 Saudi Arabia map

All Saudis are Muslims and Arab with strong Arabic traditions that are derived from the customs and traditions of the old Arabic tribes (Metz and Library of Congress. Federal Research, 1993). The five identified regional areas display the five cultures of Saudi Arabia. The differences between these regions is usually in the traditions that they inherited from their earlier generations based on a lifestyle of living in the desert (central) or those living in the mountains (south). Due to the modernization of the country and since most of the population now lives a more modern lifestyle, the Saudi culture may have more similarities between the different regions than with other Arab nations.

To fully understand the culture of the country, one must understand how the country was established and the strong role of Islam in the everyday activities of Saudi citizens. Religion plays a strong role in the lives of Saudi people. It is the birthplace of Islam and home to the holy city of Mecca, the site that 1.6 billion Muslims ritually face during their prayers. Islam is the official religion of the country and the country's governance is based on Sharia law, which is driven from the Holy Quran and the Hadith (sayings and actions of the prophet Mohammad). The aim of the education policy of Saudi Arabia is to teach the correct understanding of Islam, instilling the student with Islamic values, ideas, and principles in addition to various types of knowledge and ideas (Al-Hariri, 1987). Islam also plays a role in people's interactions with each other, their behaviours, and activities within society. The way the family interacts with each other has its root in Islam, including parents' treatment of their children, children's care for their parents, relationships with relatives and behaviours during family ceremonies.

Saudi Arabia follows the Sunni denomination of Islam. It is known as a very conservative country. Saudi families tend to be large with no less than four children per family. There is strict segregation between the sexes in both education and work. Women are not allowed to drive or travel alone. These features of daily life affect Saudi culture and the way in which people pursue day-to-day activities like eating meals and visiting doctors.

Saudi Arabia was once a poor country with very few resources, because most of its land is desert. However, after oil was discovered in 1938, the country gained control of 25% of the world's known reserves of crude oil (Bowen, 2008). Over the last 77 years, Saudi Arabia has experienced rapid development. The establishment of the Saudi Kingdom and the discovery of oil have had a dramatic impact on the economic, social, cultural, and political life of the country (Askari and Dastmaltschi, 1990). It is not uncommon for 60- or 70-year olds today to have lived in mud houses with no electricity or running water in their youth, but to now live in a modern house. The very fast Westernisation of Saudi Arabia has resulted in a modern country with advanced services, with a substantial portion of its population resistant to accepting them. Rehabilitation services, including speech and language therapy, fall into this category. Although these services are available, it appears that there are those in the public that either do not understand these services or cannot understand them as part of their medical care.

Saudi Arabian culture is influenced first and foremost by a conservative version of Islamic religion but is also shaped by the Arabic region to which Saudis belong and the tribal system

of the country. It is important to view the history of the country to comprehend how Islam in Saudi Arabia is viewed as a way of life and not only as a religious ideology. Saudi Arabia has unique cultural features—features not even seen in other countries that follow Sunni Islam. The current nation was established by expanding a kingdom through alliances with the Arabic tribes with a basis in a strict form of Sharia law (Metz and Library of Congress. Federal Research, 1993). This was the basis for several wars that were spearheaded to unite the tribes under a clearly defined Islamic mission upon which the political authority of the kingdom is founded (Metz and Library of Congress. Federal Research, 1993). From 1744 to the present as the country went through three Saudi states and wars with Egypt and the Ottoman Empire, the people of the country have been studying Islam as was taught by a highly conservative religious figure.

The influence of tribal life can help with understanding the structure and behaviours of families today. The nomadic and semi nomadic population of these regions has a strong tribal identity, and the family is the most important social institution. Socialization is within the same family or tribe (Metz and Library of Congress. Federal Research, 1993). The family is measured by the individual's capacity to live up to the socially prescribed ideas of honour (Metz and Library of Congress. Federal Research, 1993). The aim of the education policy of Saudi Arabia is to teach the correct understanding of Islam instilling the student with Islamic values, ideas and principles in addition to various types of knowledges and ideas (Al-Hariri, 1987).

The structure of the family is compatible with the structure of the tribe, in which patrilineal boundaries of the family membership are drawn around lines of descent through males. Although relationships with maternal relatives are important, the family identity as is the tribal identity is tied to the father (Metz and Library of Congress. Federal Research, 1993). Each tribe has a 'Shaikh' or a leader/prince. This title does not necessary have to be passed from father to son but has to be within the same family (Dickson, 2015). The Shaikh is an important member in any social event. He has an honorary position, sitting in a central position at any gathering. He is the first to sit down for a meal, and no one can get up and finish the meal before him. Corresponding to that, the father of the family is an authoritarian figure at the top of the hierarchy of the family and respect to him within his family echoes that of the tribe to the Shaikh.

There are unique features of the Saudi culture where applying models of health services that were designed or developed in western countries is challenging to apply. Research has

examined the role of women in Saudi Arabia and how inequality has an effect on health services provided to women (Alyaemni *et al.*, 2013), but no studies have examined the influence of sex-segregation and its impact on the patient-carer relationship or on the carer role. The context of gender segregation and traditions of mealtime are especially relevant to understanding swallowing changes in people with Parkinson's in Saudi Arabia.

Arab nations are still bound by entrenched social pressures characterized by patriarchal kinship patterns, social subordination, and ingrained male dominance, and women in Arabic countries continue to face systematic discrimination deriving from deeply entrenched societal norms combined with conservative interpretations of Islamic law. The primary expectation in Saudi families is that woman's chief responsibilities are as caretaker of the family and children. The fast pace of development in Saudi Arabia has affected women's roles in the family, society, and economy as women are becoming increasingly educated, empowered, and employed outside of the home (Karam and Afiouni, 2014). This presents a great deal of conflict between inherited cultural ideas about women's roles and the possibilities and opportunities for women in a modern society. The male-controlled biases that are rooted within cultural, religious, and legislative traditions are still deep-seated in the consciousness of the people of Saudi Arabia (Karam and Afiouni, 2014).

In Saudi Arabia, all women must wear a veil in almost all public domains (Mobaraki and Söderfeldt, 2010). Schools, universities, government offices, and many other places are gender segregated. This segregation is not a traditional practice in Saudi Arabia but was enforced during the 1980s due to political events that led to a religious reform movement called *Sahwa* (Meijer, 2010). Although there has been rapid growth in women's education and employment, the segregation issue has become more enforced resulting in most women's activities being limited to physically separated areas, a 'female sphere' where entry is forbidden for men (Le Renard, 2008).

The economy of the country allowed for these physically separated areas to exist and to spread (Le Renard, 2008). Not all government and public places have these female spheres but segregation still exists as women are not allowed to enter into certain areas that are men only. This, combined with other challenges that face women, such as the inability to drive, result in a dependency of women on men perpetuated by the family as a patriarchally organised unit. Controlling women ensures family chastity and thus family honour (Metz and

Library of Congress. Federal Research, 1993). And as stated previously, a family's honour is of great importance.

As discussed earlier, culture influences all aspects of an individual's life, this includes food and how it is prepared and served and eaten. There are also customs and traditions that are specific to different cultures within the Saudi culture. The eating and drinking social customs and traditions of the Saudi culture can be identified across all the regions. While there is some variation, the majority of the customs are the same. There are rules that dictate who serves the food, which individuals eat together, where and at which occasions food is served. These rules also govern the actual manners of eating the food. While in most regions men and women eat in separate areas but at the same time, in certain parts of the central region, the women eat after the men. Although this practice is rarely heard of, it still exists in some of the rural areas.

Mealtime customs are part of these traditions that have both the Islamic and Arabic traditional customs imbedded in them. Meals, as well as social events (e.g., weddings, gatherings to celebrate the birth of a child), are all gender segregated with allocated places for women and men. There is high respect for the older people for their position in the family, and there is always emphasis on older people being the first recipient. Meals are part of the social events that families and extended families have. Within these social events, the guests come to a sitting area called Majilis, which is where everyone gathers and greets each other. They sit on the floor, with the guests greeting the older people first before going to the second person to his right and so on. The greeting is usually a handshake and a kiss on the cheek (except for the older person who have to be kissed on their head). Lightly roasted Arabic coffee is immediately served in very small cups to the guests, with the older people being the first to be served. Dried dates are usually served with the coffee. Guests are invited to the meal area, but everyone waits for the older people to stand up first to go to the meal area (dining area).

The meal is usually on the floor, and the older people are expected to sit in the place of honour with other older people. Guests sit with their legs crossed or with one knee bent and the other underneath them; it is not acceptable to stretch one's legs in this setting. The guests usually wait until the host greets them and asks them to start. The food typically consists of lamb and rice and is placed in a central round plate that everyone eats from. No utensils are used to eat; the right hand is the only acceptable way to eat. Each person has to stretch their arm to reach for the plate. Once they are finished, there are designated washing basins for the guests to wash their hands and then they retreat to the majilis where tea is served. The prescribed ritual of eating in a Saudi family and accepting guests is pervasive throughout the

country and has important implications for people coping with health issues presented in Parkinson's.

2.4.1 The Saudi Arabian culture and health and illness

The Islamic religion represents the biggest influence on Saudi Arabian culture and therefore informs patient care in the country (Halligan, 2006). Muslims believe that illness is a test of a person's faith in God and a form of atonement for sins of the past (Sheikh and Gatrad, 2008; Bloomer and Al-Mutair, 2013). Predestination (Qadar) is an Islamic concept of divine destiny that influences the way people cope with diseases and illness. Part of Muslims' faith (Iman) is the belief that all past and future actions are already written (in the preserved tablets called Al-Lawhu 'l-Mahfuz). Therefore, Muslims understand illness and injuries as part of their predestiny (Yamey and Greenwood, 2004).

Beliefs about health reflect beliefs and knowledge of health and illness. For example, a study on different experiences of pain by Lovering in 2006 found that Saudi participants attributed pain to predestination and the belief that health is the will of God. The participants explained that illness and pain provides an opportunity for them to atone for sins and earn greater reward in the afterlife (Lovering, 2006). In a similar study, Ide and Sanli (1992) explored the attitudes of Saudi women towards health and illness and found that the women lacked an understanding of the medical causes of illness as well as the prevention of disease. The study attributed this lack of knowledge to low levels of education and Saudi cultural beliefs. Indeed, low levels of education in science are common in Saudi Arabia, as education policy focuses on religious teaching.

Considering the belief in illness as predestined, disease prevention could be perceived as a conflict with God's will (Ide and Sanli, 1992). Mobaraki and Söderfeldt (2010) reviewed the literature describing gender inequality in Saudi Arabia and its role in public health. They concluded that local interpretations of Islam as well as Saudi social customs negatively affected the health and well-being of Saudi women (Mobaraki and Söderfeldt, 2010). Jarallah and Alshammari (1999) examined the factors that impact how Saudi older people perceive health and found that (1) perception of poor health was significantly associated with lack of independence, (2) perception of poor health was twice as high in older females as in males, and (3) the inability to pray correctly was the most significant predictor of poor health (Jarallah and Al-Shammari, 1999). These studies suggest a strong effect of religion and education on health behaviours and perceptions in Saudi Arabia. They also suggest that the patient experience in Western medical facilities is substantially different for people from a

Saudi background. In addition, what can be experienced in a Western country by a person with a health issue is likely different to what is experienced in Saudi Arabia even if they have similar disorders.

2.4.2 An overview of the health system in Saudi Arabia

The health system in Saudi Arabia and its policies also has an effect on the management of swallowing in people with Parkinson's. Saudi Arabia is a welfare state and healthcare services are therefore provided free of charge (Albejaidi, 2010). The Ministry of Health (MOH) is the primary healthcare provider in Saudi Arabia (Walston et al., 2008). All citizens and expatriates living in Saudi Arabia have the right to be treated. Expatriates that work in the private sector are required to have health insurance for them to be treated in private non-government hospitals. Healthcare services in Saudi Arabia cover preventive, curative and rehabilitative health services for the Saudi population (Walston et al., 2008). Currently, medical research exists in very few institutes, and it is focused on cancer, genetic, cardiovascular, and infectious disease research. The government funds the healthcare services through its annual budget and in some cases, issues royal decrees for additional funding for special health projects (Walston *et al.*, 2008).

Although the delivery of health services is provided by the MOH network of hospitals, there are other government and private facilities that provide up to 40% of the healthcare services. Among them are the National Guard, the Ministry of Defence, the Ministry of Interior, the Red Crescent Society, and the Ministry of Education (teaching hospitals and school health units) (Almalki *et al.*, 2011; Ministry of Health, 2012). The national healthcare facility is where SLT services are provided and people with Parkinson's receive their medical management.

There are reports of maldistribution of health care services and health professionals across geographical areas of the country, with services centralized in the main cities (Almalki *et al.*, 2011). But there are challenges that face healthcare provision in the country, one is the increase in life expectancies along with the fast socioeconomic development of the country, which has put a strain on the healthcare services (Al-Yousuf *et al.*, 2002). Another is that services are centralized in main cities and therefore people with special needs, older people, and those living in remote areas are at a disadvantage in accessing healthcare services (Almalki *et al.*, 2011). In addition, long waiting times for different health services are experienced by many (Walston *et al.*, 2008). The variations in the organizations that provide

healthcare and the long waiting time has provided difficulties in developing and applying consistent regulations for quality healthcare services.

A distinctive feature of the healthcare services in Saudi Arabia is that they are provided in a westernized atmosphere. The hospitals and healthcare centres are among the few institutes in the country that have a mixed working force with no gender segregation except in waiting areas and some obstetrics wards. Ideas about patients' involvement in the treatment plan are generally advocated but difficult to implement, and subsequent cultural clashes with regard to treatment are a result.

2.5 Research Questions and Study Objectives

2.5.1 Purpose of the Study

To explore the impact of swallowing changes on people with Parkinson's in Saudi Arabia and their carers and families.

2.5.2 Research Questions

How do people with Parkinson's in Saudi Arabia experience and make sense of eating and drinking changes?

What impact do these changes have on their lives and the lives of their carers?

2.5.3 Research Objectives

To explore the influence of Saudi Arabian culture on the experiences and impact of eating and drinking changes for people with Parkinson's and their carers.

To understand the perceived eating and drinking changes experienced by people with Parkinson's in Saudi Arabia.

To understand the impact of eating and drinking changes on people with Parkinson's and their carers.

To explore the views of people with Parkinson's on the health services they receive for their eating and drinking changes.

2.6 Summary

The bulk of research on Parkinson's has focused on finding the aetiology and medical management of the disease but there is limited research on the experience of people with Parkinson's and how they perceive their own symptoms. Recently, research on Parkinson's and its impact on people with Parkinson's has intensified, but almost all of this research has been conducted in the United States and European countries. Although studies showing the importance of culture in all aspects of the disease have surfaced, no studies have reviewed the impact of Parkinson's within Saudi Arabian culture or any Arab/Islamic culture. This thesis addresses these limitations of current research.

Moreover, research on dysphagia and its impact has shown that the swallowing mechanism should be considered in the context of all the factors related to eating. The qualitative study undertaken for this thesis on the impact of Parkinson's on people with Parkinson's and their caregivers provides insights into how these populations cope with the changes they go through as a result of Parkinson's.

The literature has shown that people with Parkinson's and their carers face many challenges during the course of Parkinson's and one of these challenges is the changes to their ability to eat and drink in a manner that they perceive as acceptable. The literature has pointed to these challenges but it also has pointed to many factors that might contribute to the way the person with Parkinson's and his carer cope and experience these difficulties.

Although there are studies that point to the importance of examining culture when trying to understand how symptoms impact the quality of life of both the person and the carer none has looked at the experiences of eating and drinking changes of people with Parkinson's and the impact of these changes on both them and their families from a Saudi Arabian cultural perspective.

Chapter 3. Methodology and Methods

The purpose of this chapter is to introduce the overall design, and explain why a qualitative approach was the most appropriate for answering the research question described in chapter 2. It describes the methodology of the study design, the rationale for choosing it, the methods used to collect the data, and how they were analysed. The methodology description starts with the philosophy behind the methodology chosen and ends with a discussion of ethical issues.

3.1 Philosophical Assumptions

Multiple philosophical and theoretical traditions were explored to provide the foundation for the design of this study. To start with, the philosophical assumptions of the research need to be explained.

This research takes the ontological stance of relativism: reality is subjective, and there are multiple realities (Crotty, 1998). An ontological investigation is built on the assumption that the participants may or may not agree with each other as well as with the researcher's own views. In social sciences, ontology is concerned with the nature of social reality, or social phenomena, and the conditions under which it exists (Blaikie, 2009). Epistemology on the other hand is concerned with the nature, source and limitations of knowledge (Schwandt, 2015). This study follows the epistemological position of constructionism, which proposes that these realities are constrained by society. This study focuses on the social construction of knowledge and the social meaning of experiences. Culture has a strong influence on how a person acts and reacts to changes affecting their daily life. The way a person experiences changes in their ability to eat and drink in (what he believes to be) an acceptable manner depends on culture. By adopting these ontological and epistemological positions, the research acknowledges the importance of social interactions between people with Parkinson's and their carers and families. Additionally, axiology is the study of values (Schwandt, 2015), which contribute to the influences of social, cultural, and religious norms on human behaviour toward illness and changes. In this study, the Saudi Arabian culture and Islamic influence need to be examined as factors in the way that participants experience eating and drinking changes.

One of the goals of qualitative research, according to Maxwell (2012), is to understand participants' perspectives, how they make sense of the physical events they experience, and how their understanding influences their actions. Mason (2002) defined qualitative research as

‘characteristically exploratory, fluid and flexible, data-driven and context-sensitive’ (Mason, 2002)(p. 24). The qualitative researcher relies on participants’ views of an experience, which are affected by the participants’ own interactions with others and with their culture (Creswell, 2012).

The current study employs a phenomenological approach to provide a rich contextual description of people’s experiences in the Saudi Arabian context. Phenomenology is a philosophical approach that was introduced in 1900 by the German philosopher Edmund Husserl (1859-1938) in his book *Logical Investigations* (Sokolowski, 2000). Husserl defined phenomenology as a means of understanding how people describe experiences. This approach seeks an in-depth understanding of the meanings of experiences (Patton, 1990). It considers how people experience a phenomenon (in this study the phenomenon of changes in eating and drinking). It is a unique approach, because it provides insight into the way people experience phenomena without classifications or obstructions. Phenomenology should be considered as a style of thought rather than a philosophical school, because it is open to new experiences that may have different results (Farina, 2014).

Phenomenology is a qualitative approach (Creswell, 2012). It aims at gaining a deeper understanding of the meaning of people’s everyday experiences and is a set of “reflective descriptions” (Sokolowski, 2000). Its aim is to construct an description of human actions, behaviour and experiences (Van Manen, 1990).

There is an increase in the use of phenomenological research within health care, as health services continue to recognize the need to involve the whole person and his/her experience. Healthcare professionals need to understand patients’ perceived needs in order to meet these needs (Cohen et al., 2000; Balls, 2009).

Phenomenology studies different types of experiences, including thoughts, emotions and perceptions. The structure of these experiences involves intentionality, a term that was used by Husserl to indicate the directness of the experience. Husserl describes intentionality as how experiences are represented or intended through concepts or thoughts and ideas (Van Manen, 1990; Sokolowski, 2000).

Phenomenological research evolved from a descriptive (eidetic) approach which emphasised a 'pure' description of people's experiences, to an interpretative (hermeneutic) approach which examines contextual features of an experience in relation to other influences such as culture or

the wellbeing of a group of people experiencing the phenomenon (Matua and Van Der Wal, 2015).

Interpretative (hermeneutic) approaches allow the researcher to arrive at a deeper understanding of the experience. In health research, this deeper understanding provides the healthcare provider with the essential knowledge needed to address the patient's needs (Cohen et al., 2000). In view of the study's aim as well as the ontological understanding of the researcher, the interpretive (hermeneutic) approach has been adopted. This approach is appropriate for this study because it makes sense of the experience and behaviour of people with Parkinson's in regards to their eating and drinking changes and because this study seeks to understand these experiences within the context of the Saudi culture.

The purpose of this phenomenological study was to explore the meanings of eating and drinking changes for individuals and families. This approach is useful for this purpose because little is known about how people in Saudi Arabia experience and cope with swallowing changes due to Parkinson's. As mentioned in chapter two, Saudi culture is heavily influenced by the Islamic religion as well as traditional social roles. Thus, this research examines the influences of the axiomatic Islamic and cultural beliefs held by both the participants and the researcher on coping and health awareness. To conduct phenomenological research, the qualitative approach can be used to examine the phenomenon in the context of the culture in which it is occurring.

The general structure of this study can be described as an interpretive research paradigm using a phenomenological qualitative research approach. Qualitative traditions can be thought of as Interpretivism (Schwandt, 2015), that is, the understanding that reality is viewed by an individual according to his/her past experiences and beliefs. Interpretivism views reality as multi-layered, such that each phenomenon might have multiple interpretations (Denzin and Lincoln, 2011). This study is interpretive, because it also considers the relationship between the researcher and those being researched. In qualitative research, there is an interactive progression moulded by characteristics of both the researcher and the participants (Denzin and Lincoln, 2011).

The researcher is the instrument for data collection and analysis in qualitative interview research (Maxwell, 2012). For this reason, it is important to consider the researcher's experience, knowledge, and role in the research setting in order to understand the collection process and interpret the findings (Maxwell, 2012). According to Denzin and Lincoln (2011) researchers' perspectives and theoretical assumptions are an important addition to the theories

and research on a topic. Silverman (2013) noted that even the way a researcher frames the research question reflects his/her approach to how the world works (Silverman, 2013).

As the sole researcher for this study, I developed this study based on my experiences as a clinician working with people with Parkinson's in speech and language therapy in Saudi Arabia. Practicing for over seven years, I have worked with communication and swallowing issues, which has led to observations about a disconnect between the services available and their use by patients and families. It was unclear why patients had low attendance and did not show up for return appointments. My experiences as a speech and language therapist working with Saudi people with Parkinson's and knowledge of the Saudi culture and eating customs and traditions has made me a strong tool for qualitative data collection and analysis.

In addition, the field of speech and language therapy and evidence-based practice in healthcare in general in Saudi Arabia is different from other countries due to issues described in chapter 2. Speech therapists working in Saudi Arabia strive to use any tool, test, or material developed for speech therapy that has scientific merit; they translate it and apply it as needed in their work, hoping it will be the tool to meaningfully address their patients' needs.

There is a limited number of speech and language therapists (SLTs) in Saudi Arabia, and there is a common feeling of inexperience and a sense of being behind other SLT services in 'developed' countries. These feelings have prevented SLTs from developing a critical eye when examining new techniques. They often find themselves applying what they have read exactly as the textbooks say. There are multiple factors that affect the way SLTs apply both their assessments and their therapies, and these factors need to be examined more closely. Those who attend the SLT clinics in question are not just people with Parkinson's: they are *Saudi* people with Parkinson's. The lives they are living are not the same as those lived by people with Parkinson's in other countries. SLTs in Saudi Arabia often see results that are different from what has been published in the studies and books they have read. Through the literature review and experiences of working with people with Parkinson's, it became evident that the Parkinson's-swallowing relationship goes beyond mechanical issues. The processes of eating and drinking, the social setting of meals, and the carer all contribute to this relationship. Eating and drinking customs have a strong influence on the way people experience them. While there may be some similarities between cultures, it is important to examine meaning making within a country so that appropriate treatments can be developed and health behaviours can be understood.

3.2 Study Design

This study involved the following: (a) a focus group conducted with speech and language therapists in Saudi Arabia, (b) semi-structured interviews with people with Parkinson's, and (c) semi-structured interviews with the carers of people with Parkinson's. All included open-ended questions as this approach allows participants to talk about their experiences with minimal researcher intervention. The study was designed to be an iterative process. The focus group method, which was used during the initial stage of the data collection, was used with SLTs to gain more breadth in the scope of issues that might help in conducting the semi-structured interviews for the people with Parkinson's and the carers. They also served to reduce the influence of the biases of the researcher on the quality of the data. In total, there were three data collection visits to Saudi Arabia to collect the data, analyse it, reflect on it, refine data collection strategies, and collect and analyse more data.

The methods of data collection can be viewed in stages, an iterative process, with each data collection stage timed and designed based on the findings of the earlier stage. This allowed the development and refinement of the study according to the key concepts that were emerging from the data. For example, at the initial stage, the research included a very limited definition of 'swallowing difficulties'. The analysis of this stage showed that a better characterization of the phenomenon (a more common meaning that involves all activities that participants might struggle with) was to call it 'eating and drinking changes'. In the next stage, central themes were identified, and the final stage involved collecting additional data to refine, illustrate, and expand on the themes as well as to achieve data saturation, ensuring that no new themes emerged. The initial interviews that were done in the first data collection trip were also used to identify challenges that need to be addressed during the interviewing process to ensure quality data. Figure 2 illustrates the iterative process of data collection and data analysis.

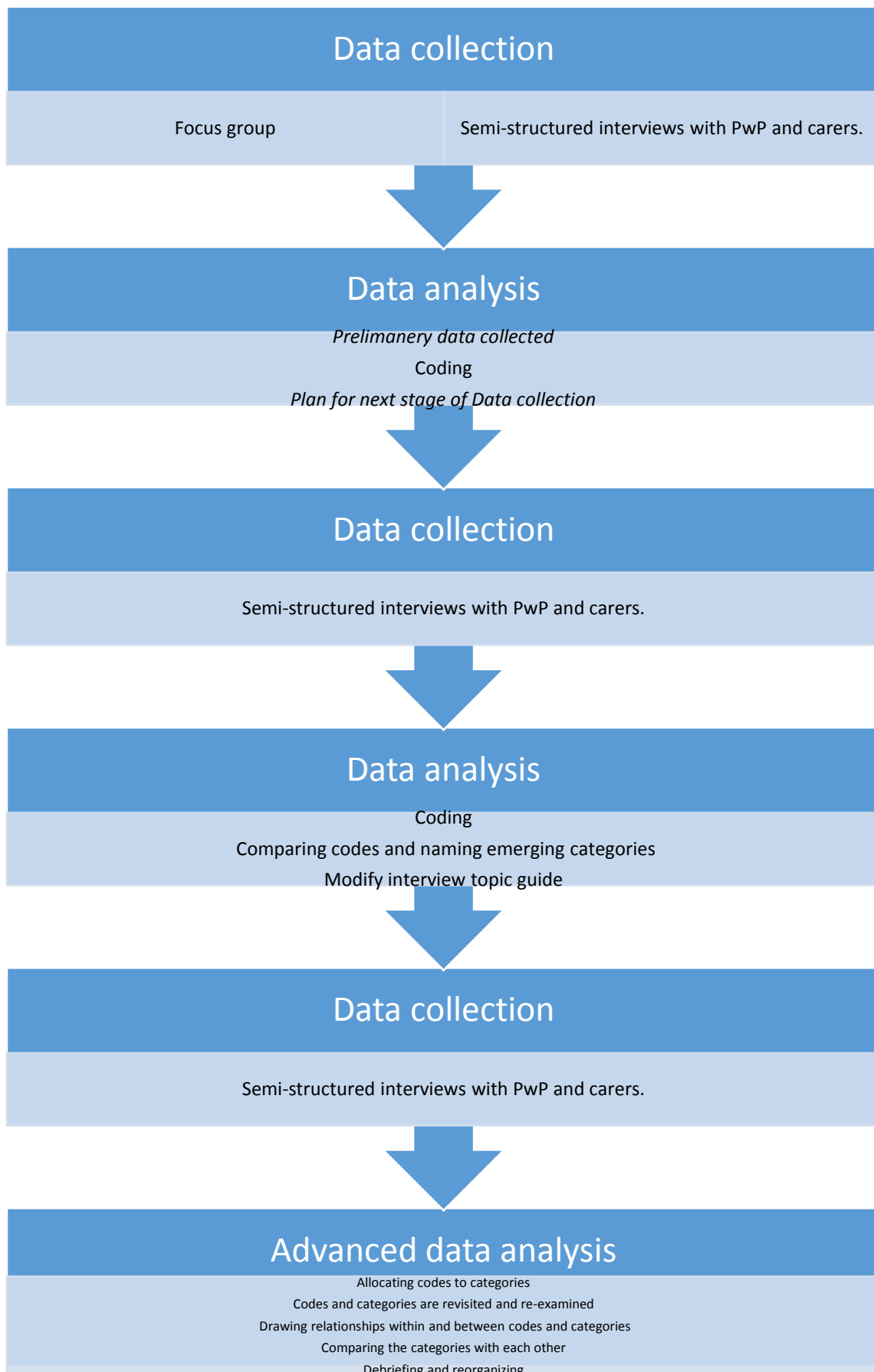


Figure 2 Data collection and analysis

The researcher was based in Newcastle, United Kingdom and travelled to Riyadh, Saudi Arabia to collect the data for the study. The first trip was from May 2013 to October 2013. The initial interviews and focus group were conducted at King Fahad Medical City (KFMC) from both the movement disorders clinic and the swallowing clinic. The second trip was from May through July 2014, and the third was from December 2014 to January 2016, which involved collecting data at the National Guards Hospital.

Table 2 Timeline of data collection

Data collection trip number and dates		Methods used	Participants	Location
1st	May 2013 to October 2013	Interviews Focus group	PwP 1 to 4 Carers 1 to 2	KFMC
2nd	May 2014 to July 2014	Interviews	PwP 5 to 13 Carers 3 to 10	KFMC
3rd	December 2015 to January 2016	Interviews	PwP 14 to 21 Carers 11 to 18	NG

PwP = people with Parkinson's

The purpose of the first data trip was to develop effective recruitment strategies and collect preliminary data to inform and refine the interview process. The initial trip took much longer than the other trips due to issues with conducting the interviews and focus groups. There were challenges to recruitment and issues with the location of the interview, which will be discussed at the end of this section in preliminary analyses of the interviews. Although it was the longest data collection trip, it had the smallest number of participants. These preliminary data were used to enhance the topic guide and interviewer skills and led to improved recruitment procedures.

3.3 Sampling

Because qualitative researchers are focused on acquiring personal accounts from people who have experienced a phenomenon first-hand, qualitative sampling is not intended to be statistically representative (Ritchie et al., 2013). It assumes that knowledge is dynamic and context-dependent and, therefore, not generalizable to all or most cases (Taylor and Francis, 2013). Qualitative studies use a variety of sampling techniques to ensure that the data they

collect are information-rich. One of the key features of sampling in qualitative research is that sample sizes are relatively small. This feature allows in-depth investigations into the phenomena being studied (Ritchie et al., 2013). A sample size of between 15 and 30 individual interviews is common in research that aims to identify patterns across data (Braun and Clarke, 2013). It is difficult to determine the size of the sample at the onset of the research, since the ongoing process of collecting and analysing data will determine the final sample size (Silverman, 2010). The final sample in qualitative research is reached when no new information can be extracted from the data pool, that is, “saturation of data” (Mason, 2010). This as well as logistical reasons (e.g. time and cost) influenced the plan for a sample size of 15 people with Parkinson's and 15 carers, with the understanding that this number might increase or decrease.

This study used purposive sampling to identify individuals with Parkinson's who had experienced some form of eating or drinking difficulty. Purposive sampling occurs when a researcher actively selects the most productive sample to answer the research question (Marshall, 1996). Patton identified a number of strategies under purposive sampling, one of them is the homogenous purposive sample which is sampling that aims to obtain homogeneity allowing the sample to describe a sub-group (PwP, Carers, SLT) (Patton, 1990).

The criteria for inclusion were (a) individuals of Saudi Arabian nationality (b) with confirmed medical diagnoses of idiopathic Parkinson's (c) who were currently living and had lived all of their lives in Saudi Arabia. Their diagnoses had to have been made by a neurologist at least three years prior to the start of the study so that the participants were no longer in the diagnostic phase of the disease or still adjusting to their new condition. This ensured that the participants had been fully experiencing the symptoms of Parkinson's for a substantial amount of time. The participants had to have been following or visiting a neurology clinic within the study sites (to facilitate the study's access to medical information), and could not be currently hospitalised. No age, gender, or regional limitations were used for inclusion criteria.

Specific criteria were set so as to access participants regardless of whether they had reported swallowing changes or whether their neurologists had flagged or referred them for swallowing problems. This allowed for both those with a recognized swallowing problem who have been to a SLT and those who might have some eating and drinking issues that they (or their doctor) were unaware of. Based on the observations and interviews conducted at KFMC during the first stage of data collection, it was found that a number of people with Parkinson's who visited the neurology clinic were not referred to swallowing services but

had, in fact, been experiencing different degrees of eating and drinking difficulties. Thus, by restricting recruitment to the swallowing clinic alone, the study would have accessed only part of the Parkinson's population who seek help in the country—those that are aware that they have a problem and have asked for referral to specialised services—and would have missed all patients at different stages of the disease, who could have been experiencing different degrees of swallowing problems associated with Parkinson's or who had not been referred to the swallowing clinic by their neurologists because they did not complain or did not ask to be referred or any other reason.

The inclusion criteria for the carers was that they had to be the primary carer of the person with Parkinson's in the study. In cases in which the person with Parkinson's did not need or have an immediate live-in carer, the family member who was the most frequent visitor was chosen. If domestic help was identified by the family as the carer, only Arabic or English-speaking helpers were interviewed. All carers were required to be of Saudi nationality, except in the case of domestic help.

3.3.1 Recruitment

Specialized medical services in Saudi Arabia are centralized to the major cities, and Riyadh, as the capital, is the centre for all Parkinson's-related services. By interviewing participants from two sites, a more diverse sample and a larger population was accessible to sample from. King Fahad Medical City (KFMC), a Ministry of Health referring centre, and National Guards hospital (NG), a specialised hospital for National Guard employees, both receive referrals from clinics all over the country. KFMC predominantly provides medical services for civilian citizens, while NG provides the same services for military citizens and their families. At both sites, participants were recruited from the neurology/movement disorders clinics, and at the KFMC site, participants were also recruited from the swallowing clinics. Therefore, the researcher was able to access both patients who had already been identified as having swallowing problems and patients who did not complain or had not been referred for swallowing problems.

The researcher shared the inclusion criteria with the neurologist and medical team by communicating with them via telephone during the initial stages of the study and later with a meeting with the neurologists and the rest of the medical team during the first day of each data collection visit. An information sheet about the study was also given to the medical team. The participants were initially identified by the neurologist and the medical team running the movement disorders and neurology clinics at both sites (KFMC and NG).

To maximise diversity in terms of Parkinson's stage, gender, and age as well as to encompass as broad a representation of the Saudi population as possible, other inclusion criteria were also employed. To represent the sub-cultures of Saudi Arabia as much as possible, participants were finally selected after I reviewed the charts of the potential participants and took region into account. Once a potential participant was identified, the neurologist asked him/her if he/she might be interested in participating in the study. If the participant gave a positive response, the neurologist contacted the researcher with the potential participant's basic information.

The final sample included 21 people with Parkinson's and 18 carers. Of the 21 participants, three did not have a carer. Participants were assigned pseudonyms to protect their identity. The three speech and language therapists included two males and one female, with 13, 7, and 3 years working as a SLT respectively. Their ages were 38, 30, and 27 and they had all worked with people with Parkinson's during the majority of their careers.

Table 3 People with Parkinson's participants

Interview Code	Gender	Age	City/Province	Education Level	Employment Status	Matrimonial status	H&Y stage	Years since diagnosis	Ref to SLT	Domestic help	Carer Code	Relationship of carer	Carer age	Live in(out)
Saleh	M	53	Riyadh/Central	HS	Businessman	Married	2	5	No	Yes	No Carer			
Noura	F	74	Riyadh/Central	Illiterate	Unemployed	Widow	4	12	Yes	Yes	Reem	Daughter	26	Live in
Hussa	F	73	Riyadh/Central	Illiterate	Unemployed	Married	3	8	Yes	Yes	No Carer			
Naif	M	71	Riyadh/Central	Illiterate	Retired civil	Married	3	15	Yes	Yes	Waleed	Son	32	Live in
Ibrahim	M	55	Riyadh/Central	BSc	Administrator	Married	2	5	No	Yes	No Carer			
Fatimah	F	68	Skaka/North	NFE+Q	Unemployed	Widow	2	3	No	Yes	Fahad	Son	31	Live in (part time)
Ahmed	M	58	Onaizah/Alqaseem	High	Retired civil	Married	3	8	No	Yes	Hailah	Wife	46	Live in
Saad	M	57	Alrass/Alqaseem	High	Retired civil	Married	3	3	No	No	Raid	Son	26	Live in
Mansoor	M	62	Quwayah/Alqassem	9 th grade	Retired civil	Married	3	7	Yes	Yes	May	Daughter	22	Live in
Ali	M	66	Hail/Hail	9 th grade	Retired civil	Married	4	17	No	No	Adel	Son	38	Live out
Haya	F	72	Abha / South	NFE	Unemployed	Married	4	9	No	Yes	Sameera	Maid	26	Live in
Nasir	M	85	Maddenah/West	High	Retired civil	Married	4	13	Yes	No	Huda	Daughter	34	Live in
Monira	F	61	Dammam/East	9 th grade	Unemployed	Married	3	10	Yes	Yes	Amal	Daughter	26	Live in
Aziza	F	70	Riyadh/Central region (R)	NFE+Q	Unemployed	Married	2	5	No	Yes	Saud	Son	40	Live in
Abdulrahman	M	78	Riyadh/Central region	BSc	Retired businessman	widow	3	11	Yes	Yes	Asma	Daughter	39	Live in
Mohameed	M	38	Arar/Northern region (R)	HS	Unemployed	single	4	14	No	Yes	Turki	Brother	21	Live in
Abdullah	M	74	Khobar/Eastern region	HS	Retired military	Married	3	8	Yes	Yes	Dalal	Daughter	33	Live in
Abdulaziz	M	81	Riyadh/Central region	9 th	Retired military	Married	5	16	Yes	Yes	Manal	Daughter	42	Live in
Khaled	M	56	Macca/West (R)	HS	Retired military	Married	3	7	No	Yes	Yousef	Son	30	Live out
Aisha	F	77	Riyadh/Central region	NFE	Unemployed	widow	4	10	Yes	Yes	Hadeel	Daughter	28	Live in
Fayza	F	68	Buridah/Alqaseem	6 th grade	Unemployed	Married	4	8	Yes	Yes	Rashid	Son	36	Live in

NFE: No formal education NFE+Q: No formal education but can read Quran HS: High School BSc: Bachelor degree (R) Currently living in Riyadh

H&Y: Hoehn and Yahr scale

Table 4 Carers participants

Interview Code	Age	City/Province	Education Level	Employment Status	Carer of	Relationship to PwP
Reem	26	Riyadh/ Central region	Bsc	Unemployed	Noura	Daughter
Waleed	32	Riyadh/ Central region	HS	Government employee	Naif	Son
Fahad	31	Skaka/ North	HS	Government employee	Fatimah	Son
Hailah	46	Onaizah/ Alqaseem	6 th grade	Unemployed	Ahmed	Wife
Raid	26	Alrass/ Alqaseem	Diploma	Government employee	Saad	Son
May	22	Quwayah/ Alqasem	HS	Student	Mansoor	Daughter
Adel	38	Hail/ Hail	Bsc	Government employee	Ali	Son
Sameera	26	Abha / South	HS	Unemployed	Haya	Daughter
Huda	34	Maddenah/ West	HS	Unemployed	Nasir	Daughter
Amal	26	Dammam/ East	Bsc	Unemployed	Monira	Daughter
Saud	40	Riyadh/ Central region	HS	Military job	Aziza	Son
Asma	39	Riyadh/ Central region	Msc	Stockbroker at home	Abdulrahman	Daughter
Turki	21	Arar/Northern region	HS	Government employee	Mohameed	Brother
Dalal	33	Khobar/Eastern region	HS	Unemployed	Abdullah	Daughter
Manal	42	Riyadh/ Central region	Bsc	Work as a teacher	Abdulaziz	Daughter
Yousef	30	Macca/ West (living in Riyadh)	Bsc	Civil Job Retired	Khaled	Son
Hadeel	28	Riyadh/ Central region	HS	Student at University	Aisha	Daughter
Rashid	36	Buridah/ Alqaseem	Bsc	Military job	Fayza	Son

HS: High School BSc: Bachelor degree

3.3.2 Participants with Parkinson's

The twenty-one participants with Parkinson's who were interviewed ranged from thirty-eight to eighty-five years old; thirteen were males, and eight were females. Out of the thirteen males, eleven were married, one was single (the only one who had early-onset Parkinson's), and one was widowed. Of the eleven married men, one had two wives, one had four wives, and the rest (nine men) had one wife each. One of those nine men was the carer of a bedridden wife. Out of the eight females, five were married, and three were widowed. Only one of the married females was in a polygamist marriage; she was a first wife to a man with two wives.

None of the participants lived alone. All lived in family homes that either they or their children owned. Between seven and twenty-six people lived in these homes; two participants refused to answer questions related to the number of people who lived in their homes. The researcher anticipated resistance to mentioning the number of people in a house especially in big houses. A large number of people in a house is considered something that might attract the evil eye. Therefore, at every interview, the researcher intentionally mentioned the purpose of the interviews and the limited number of people that will review the interviews (the researcher and supervisors only), as well as assured participants of the anonymity of those interviewed. Despite these precautions, there were still participants that would not answer the question about the number of people in the household. This will be discussed further in chapter five. Fourteen of the twenty-one homes had one or more domestic helpers. All of the female participants had female domestic help, and one of the male participants had a male nurse. None of the domestic helpers spoke Arabic fluently, while the male nurse could not speak Arabic at all. Most of the communication between the domestic help/nurse and the participants and their families was done through broken Arabic, English, and/or gesturing.

Only two of the female participants had formal education: one had a sixth-grade education, and one had a ninth-grade education. The rest of the females were illiterate, although two have since enrolled in the government adult-literacy programme, and now are able to read passages from the Quran. In contrast, only two of the thirteen males were illiterate. The rest had had formal education in their youth: three had a ninth-grade education, six had high-school diplomas, and two had university (bachelor's) degrees.

None of the female participants worked or had ever worked. The three widows received their husbands' monthly retirement pensions; the remainder of the female participants lived with (and were provided for) by their children. For the male participants, nine were retired, one

worked in educational services (he had been a teacher, but after the Parkinson's diagnosis, was doing administrative duties only), one (the early-onset Parkinson's case) had never worked, one was a businessman, and one had owned his own company, but his son had taken over after the onset of Parkinson's. Of the nine retired males, five had retired from military service, and four had retired from civil government jobs.

Participants represented a variety of regions in Saudi Arabia, with nine from Riyadh city and central Saudi Arabia, and one from each of the following places: Skaka in the north, the cities of Buridah, Quwayah, Onaizah, and Alrass in the northcentral region of Alqaseem, Arar in the Northern region (living in Riyadh), Hail from Hail region, Maddenah in the West, Macca in the West (who lives currently in Riyadh), Abha in the south (currently living in Riyadh), Khobar in the eastern region, and Dammam in the East. Of the twenty-one, eleven were referred to the swallowing clinic, and ten were not.

3.3.3 Carers

The ages of the carers ranged from twenty-one to forty-six years old; ten were females and eight were males. The carers interviewed included nine daughters, seven sons, one wife, and one brother. Sixteen carers lived within the same house as those they cared for, while two lived elsewhere. It is important to note that those two who lived elsewhere (sons of two male participants with Parkinson's) had identified themselves as carers, but during the interview, I determined that in reality their sisters performed the actual day-to-day care of their fathers. Part three of this chapter discusses in more detail how the role of 'carer' is defined in Saudi Arabia, and discusses the differences between that role and the universal (standard) definition of caregiving that is used elsewhere in the world.

All carers had formal education. Of the eight males, three had university degrees, while four had high-school degrees; one had a diploma. All of the female carers also had formal education: one had a master's degree, three had a bachelor's degree, five had high-school diplomas, and one had a primary-school-level education (sixth grade).

In terms of work, all male carers worked: two had military jobs, five had civil government jobs, and one worked in the private sector. Of the female carers, only one female carer worked (in the educational sector), while two were studying to attain their university degrees at the time of the interviews. One daughter worked from home (as a stockbroker) while sharing the care of her father with a male nurse. The remainder of the female carers did not work.

3.4 Speech and Language Therapists Focus Group

To explore issues experienced by other speech and language therapists than the researcher who have worked with people with Parkinson's and their carers, a focus group was conducted. Focus groups involve collecting data from multiple participants at the same time (Braun and Clarke, 2013) in order to stimulate discussion, revealing new perspectives for further exploration (Bradbury-Jones et al., 2009). They are an excellent method to elicit a wide range of views on an issue (Braun and Clarke, 2013), and in this study, they served to support and expand on the experiences of the primary researcher as a SLT in Saudi Arabia. One of the major aims of focus group analysis is identifying areas of agreement and disagreement (Kidd and Parshall, 2000). The focus group of SLTs was a source of preliminary data in that it provided their explanations of why they think people with Parkinson's and their carers act as they do (Morgan, 1996). The SLTs who worked with the target population were a good group to hypothesise about reasons behind behaviours, thus improving the comprehensiveness of the interview questions for the target population.

It is useful that the people in a focus group know each other before the discussion as this maximizes the interaction between participants as well as potentially provides some access to shared group culture (Green and Thorogood, 2013). The SLTs that participated in the focus group all knew each other as they worked at the same clinic at KFMC. While a larger focus group would have been ideal, the inclusion criteria for this study were that the SLTs should be working with people with Parkinson's during the time of the focus group so that reporting would be on recent experiences, reducing memory bias. As the SLTs working at KFMC work in teams, the Adult Communication and Swallowing Team has only three SLTs who fit this criteria. Three is an acceptable minimum number for a focus group (Barbour, 2008).

The topic guide for the focus group included questions and prompts to elicit the challenges speech therapists experience when assessing and working with people with Parkinson's, specifically, what they experience when applying treatment programmes, how people with Parkinson's respond to therapy programmes, and their willingness to participate in them. All questions were open-ended, though the researcher used a list of prompts to obtain more details from the participants. This list can be found in Appendix A

The focus group was conducted in a therapy room at the speech and language therapy department. It was audio-recorded and conducted in Arabic, but because the SLTs were working in an English-speaking facility, there were words and phrases that were said in English. The focus group began with a prepared welcome message in which the research and

its purpose were reviewed, the purpose of the focus group was presented, and participants were reminded that anything discussed would be confidential. They were also given an explanation for why the discussion would be audio-recorded. The data collection started with a friendly and easy chat; rapport was easily established as we have all worked together at various times. This led to asking the first question in the topic guide about their experience working with people with Parkinson's, specifically their work and what they do when they have patients with Parkinson's. The SLT were very polite at the start and were waiting for the older SLT to start answering. The conversation became more relaxed and the discussion more detailed. The discussion included issues on patients' compliance and attendance to SLT programmes, influence of Islam and carer related issues. I ended the focus group with a brief summary about what we discussed and asked if there was anything they needed to add that we had not discussed. The SLTs confirmed issues that were discussed but nothing new was added. And finally I thanked the participants for participating and invited them for a light snack and coffee in the next room.

3.5 The Interview Process

Face-to-face semi-structured interviewing was the main method of data collection, chosen because it was the most appropriate method to answer the research question. Interviewing can get closer to the participant's perception and capture the meanings from their point of view (Denzin and Lincoln, 2011). A semi-structured format was used because it involves the interviewer asking a list of questions but there is still room for the participants to raise issues that the researcher has not anticipated (Braun and Clarke, 2013). This is different from the structured interview format in which both questions and response categories are predetermined by the interviewer (Braun and Clarke, 2013). This would not have allowed the participants to go into details about the issues that they face and there would have been no room for other issues to surface that might not have been covered or thought about by the researcher. Considering the limited literature available, semi-structured interviews were used so that the participants would shed light on issues that were not discussed in previous research because they are strongly participant-led (Braun and Clarke, 2013).

Because the interviews were semi-structured, it allowed the interviewer to have an interview schedule that include a number of open-ended questions to be asked in each interview but also enable flexibility within these interviews. There were questions that the interviewer planned to ask that were informed by the literature, but there were also themes from the previous interviews that emerged, which required further investigation in subsequent interviews. This

allowed flexibility as it gave the interviewee a chance to talk freely and the interviewer to further prompt different subjects appeared.

The interviews were conducted using an iterative process, with each interview conducted being a continuation of previous interviews. After each interview, analysis influenced the topic guide for the next interview. The researcher also made changes to the interviews to accommodate challenges concerning during the interview. These challenges will be explored more deeply in both chapter 4 and 5.

The interviews with the people with Parkinson's lasted between 36 and 132 minutes while the carer interviews lasted between 70 minutes and 2 hours. All of the interviews were located in the hospitals in which the people with Parkinson's had appointments (except one carer interview, which was held in a coffee shop).

Selecting a natural setting for the interviews can maximise the quality of the data collected because it puts the interviewee more at ease. People are usually most comfortable at home. However, due to the culture of Saudi Arabia, this was not possible. In Saudi Arabia, if the researcher would have visited the participants at home, she would have been treated as a guest; that is, she would have sat in the guest quarters of the home and would have been offered a lavish meal. She also would have had to sit in the female section of the home, even if the participant was male. At a hospital, however, the interviews could be much more relaxed and less gender segregated. Hospitals in Saudi Arabia are designed based on the Western influences of American and European hospitals, so they do not have male/female segregation, and patients are used to seeing women and men working and sitting in the same rooms. Therefore, the best place to conduct the interviews was determined to be at the clinics where the people with Parkinson's were being seen. With this determined, I still asked the participants where and when they wanted the interviews to be and, as expected, all the participants except one carer asked to be interviewed in the clinic before or after their appointment. One carer suggested a popular coffee shop, and the interview was conducted there.

The aim in interviewing the participants was to identify the core issues with which they might be struggling regarding eating and drinking. These could include issues the participants had never complained about or discussed with their medical team for reasons related to the Saudi culture, their religious beliefs, and/or any unknown reason. In the carer interviews, the aim was to understand the carers' roles in the care of the patients with regard to eating, drinking, and related activities, such as cooking and shopping for food.

The interviews began with greeting the participants and reminding them of their previous conversation (i.e. the consent form handling and the researcher's introduction of the study). Participants gave permission to turn on the audio recorder at the beginning of the interview, even though they had already consented to being audio-taped. Since some of the participants were not aware that they had Parkinson's, it was important not to mention Parkinson's until the participant identified his/her Parkinson's by using the Arabic or English word for Parkinson's.

The interviews started with very general questions. The researcher mostly asked the participants to talk about themselves, their families, their health and/or their reasons for visiting the clinic. These questions led to a more detailed discussion about the participant's health. If the participant mentioned Parkinson's, the researcher would pick that up and try to explore how much the participant understood Parkinson's and the changes experienced with the disease. The initial questions also led to questions about the participant's life and a discussion about meals and eating. This last part was where the discussion aimed to become deeper. The questions here explored issues with eating and drinking safely and social issues related to eating and drinking. These questions changed after analysing the interviews throughout the data collection process, and the subsequent questions were framed differently based on the previous interviews' answers or the themes that were emerging during the data collection process. Appendix B is the interview guide used with people with Parkinson's in the initial interviews while appendix C show the change in the topic guide in the later stages of data collection (appendices D and E show the same process of change but to the carer interviews).

3.5.1 Reflecting on the Interviews

My skills as an interviewer improved throughout the process. The transcripts reveal that less intervention was needed as time went on within and between interviews for participants to give more detailed answers. Over time, I became better able to give useful prompts that allowed the participants to talk at further length about their responses. For example, phrases like "can you explain more?" and "can you give me an example?" were used to encourage the participants to talk more. I used the participants' answers, not the topic guide, to direct the interviews. The topic guide was used to be sure I covered the areas that needed to be discussed, not to guide the discussion.

The first interviews were slower in pace than later interviews. The interview tended to start with general questions with the expectation that the participants would introduce the issues

they were having with eating and drinking, but this led to longer time leading to the questions that are more detailed. The interviewer later found out that with people with Parkinson's it is important not to tire them. With time, the interviews changed to beginning with general questions to help the participants ease into the interview and become more relaxed but time was kept more carefully. Once the participants seemed relaxed, questions that related to the topic of the interview were addressed more quickly.

Similarly, the pauses in the first interviews were very uncomfortable as an interviewer and therefore I tended to jump and fill awkward silences. It became clear that restraint was required such that there was silence, and the participants tended to fill the silent gap. I also used sounds like 'hmmm' and 'aha' and waited after to let the participant know that more was expected. I also developed a habit of sitting and writing on the pad during some of the pauses so that the interviewee felt they could add more. A notepad and a pen were used to make notes on non-verbal cues, facial gestures, and other important aspects that could not be captured on the audio recording. Challenges to interviewing can be expected in many interview settings but especially in interviewing people with speech and language issues, and non-verbal cues are important to capture.

After initial interviews, I met with my supervisory team, which helped in addressing the challenges during the data collection period. In the first data collection trip, each interview was discussed, and the issues that the interviewer had were explored in order to improve my interview techniques.

The cycle of interviewing, transcribing, translating, analysing occurred throughout most of the fieldwork. Since the participants chose the time convenient to them to be during their doctor appointment and since the doctor only had two clinics a week, there was often more than one interview in a clinic day, and the long process of translating and transcribing all of the interviews before the next clinic day was sometimes unachievable. This resulted in a pile-up of interviews waiting to be transcribed, translated, and analysed while more interviews were collected. The long periods between data collection trips allowed time to finish these steps and reflect on their analysis before starting the next visit.

3.6 Data collection challenges

3.6.1 Issues with recruitment

Of the first five potential participants that were scheduled for an interview, none of them showed up. The initial recruitment plan was for the neurologist or a member of his team to identify potential participants and make initial contact with them so that their contact information is passed to the researcher; this was not an effective recruitment plan. When the recruitment strategy changed, it was more effective, with a response rate of 100%. For the revised strategy, I made the initial contact. Potential participants were identified by their files and contacted individually. Participants were introduced to the research and interview arrangements were made that were suitable to the participants and their carers. This indicates that there was a barrier to the initial method. Although it is not clear what the barrier was, the response rate was improved by approaching the participants directly. It may be that the initial contact for research with this population should be made by someone who can answer all the questions as well as arrange the interview to be suitable to the participants' needs.

Another important observation in the recruitment process was the challenge of introducing the study to the patients themselves. To ensure confidentiality in research conducted in health care in general, researchers contact the patient directly. In the case of the first four interviews, this was a challenge in many ways. First, the telephone numbers in the medical files for most participants with Parkinson's were for the carers. When asking to speak to the person with Parkinson's, their sons/daughters said they could talk on their behalf. Due to confidentiality issues, it was important to insist on speaking to the person with Parkinson's. This was difficult because even when insisting on speaking to the person with Parkinson's, that person referred the call back to their carers and said they will be the one deciding if they participate or not. Efforts were made to get verbal consent from every participant with Parkinson's to participate and to have the carer sign on their behalf before talking with the carer. Nevertheless, all of the participants with Parkinson's referred the call to the carer with their consent.

This also was the situation with the consent forms and the information sheets; both were handed to the person with Parkinson's who handed them to their sons or daughters. The people with Parkinson's were the intended participants for this study, and the assumption was that they would be making decisions and determining consent for themselves. This was not the case. The grown children were the ones who read the information sheet and signed the consent forms. This meant a shift to discussing the study with the son or daughter instead of

the participants with Parkinson's and having the son or daughter as the one who signed the consent form. These behaviours were a finding in themselves. They foreshadowed issues unique to this population with regard to medical treatment and parent-child roles that influence people with Parkinson's and their carers' perspectives on changes in eating and drinking. In the case of the first four interviews, the participants with Parkinson's deferred to their children with regard to decision making in healthcare situations as well as in participating in a research study.

3.6.2 Issues with interviewing people with Parkinson's

A great deal of information was extracted from the focus group with the SLTs because the participants were the researcher's colleagues, and they understood the research and the purpose of the focus group. The carers' interviews went more smoothly than the interviews with the participants with Parkinson's; conversations with the carers provided a lot of information and themes. It was the interviews with the participants with Parkinson's that were most challenging. Although the participants with Parkinson's were willing to be interviewed, the researcher's initial inexperience with interviews was a barrier. These were people with Parkinson's who already had communication disorders and were not willing to use long sentences, which is part of the profile of Parkinson's. Open-ended questions were asked, but the replies were very short or single words, so trying to help the participant elaborate was difficult. This showed that the prompt list needed significant modification and expansion.

Another way the issue of brief responses was addressed was by using more pauses and facial expressions to indicate waiting to hear for more. Starting the interviews with the participants with Parkinson's with questions about why were they visiting this particular clinic seemed more effective in generating detailed answers about their Parkinson's. This process was used to build rapport while focusing on the setting and led to a discussion pertaining to the symptoms and management of problems. This made an effective transition to talking about the changes they experience with eating and drinking.

Another significant issue that showed up in these interviews was a unique feature in Saudi conversation. Saudis tend to answer questions with a specific Islamic phrase instead of answering them directly. This has implications for research interviews in that additional prompting may be necessary for clarifying meaning. For example, the usual answer to 'How is your health?' is 'Thanks to Allah', which might mean, 'I am healthy thanks to Allah' or 'I am not well, but we are still thankful to Allah'. In a social context, both interpretations are

acceptable. But in the context of an interview for scientific research, these kinds of answers require expansion, and researchers interviewing Saudis will need to consider this.

There were other issues noted in the initial phase of fieldwork that later enhanced the following interviews. The information that the researcher collected prior to conducting the interviews with the participants with Parkinson's and their carers seemed to be sufficient, but during the analysis process, it was apparent that more information was needed than the conventional demographic information of age, gender, duration of diseases, and so on. Many responses needed further detail to interpret and fully understand the experiences the participants were narrating. As a result, subsequent interviews collected more demographic information such as the region the participants (both participants with Parkinson's and carers) belonged to (both the region he/she is originally from and currently living in so as to reference their subculture), their education level, employment status, which can lead to a discussion regarding the impact in relation to work or education, and the number of people in the house, including the presence of domestic help which would help in interpreting the burden of care. Appendix F show the data form used to collect this information.

3.7 Data Preparation and Analysis

The data analysis was conducted using thematic analysis described by Braun and Clarke (2013), who described a six-phase analysis method which was used for this study. It included (1) familiarising myself with the data by rereading the transcripts several times noting first thoughts, (2) generating initial codes, by coding the first interesting features of the data that appear, (3) search for themes and group the codes into potential themes, (4) review the themes and check them against the data to ensure fit and representation in the data, (5) define, name, and refine the themes. and (6) write up the analysis using examples from the data for each theme (Braun and Clarke, 2013).

These steps imply a smooth set of actions, but analysis for this study was complex and messy with overlap of the steps above. As was stated by Rapley and Silverman (2010), a researcher needs to develop a qualitative analytical attitude while analysing and not just follow a list of steps or procedures (Rapley and Silverman, 2011). The following are the stages that the researcher used for both data preparation and analysis.

3.7.1 Transcribing and translation

The interviews and focus group were audio-recorded and transcribed verbatim in Arabic and then translated into English. The audio-recordings were transcribed by the researcher who is also a SLT, therefore issues with speech intelligibility due to the person with Parkinson's altered speech were handled by the researcher and not the translator. The researcher was able to listen to the recordings, transcribe them to the best of her abilities with her trained ear as a SLT working with people with Parkinson's. The focus group was transcribed and translated with no involvement from the translator. I reviewed all the transcripts before coding for the thematic analysis described by (Braun and Clarke, 2013). This type of analysis is useful for developing researchers, as it introduces them to analysis and helps to develop their skills in working with different types of analysis.

During the first data collection phase, the translator attended a one-on-one workshop with the researcher, during which the details of the translation process were clarified with examples of the translations of the preliminary study interviews for her to learn from. The translator was instructed on how to handle religious phrases, difficult- or impossible-to-translate words and sentences, and words she did not understand (Saudi Arabia has many dialects, and some dialects have words that are not understood by speakers of other dialects).

The sequence of interview, transcription, and translation was adapted from a paper by Suh et al., who described three types of translation in research (Suh *et al.*, 2009). The type chosen for the present study allowed the supervisors of this study (all non-Arabic speakers) to participate in every aspect of the analysis process and to review the transcripts during the supervisory meetings. The finalised English versions of the transcripts were edited to include pauses, non-speech sounds, change in voice tone, and any nonverbal cues noted by the interviewer. This final version of the transcript was coded for analysis.

3.7.2 Reading

The interviews and focus groups were conducted as well as transcribed by myself, this process as well as reading and re-reading the data even as the interviews were still ongoing allowed familiarization with the data. With immersion as the first stage in the analysis process (Green et al., 2007), I continued to read and re-read the interviews both in Arabic and English.

3.7.3 Coding and building the themes list

An important stage in the analysis process was the coding. A code is a word, phrase, sentence, or a part of a conversation that is extracted from the data and used to interpret meaning and detect patterns in the data (Saldaña, 2015). The researcher carefully considered and reviewed every part of every interview, and there were some quotes which were assigned more than one code. This resulted in a long list of ‘basic’ codes which were later grouped into broader codes, called ‘master themes’. From these, even broader themes, labelled ‘global themes’, were identified. The researcher completed all of the coding by hand, using Post-It notes and coloured pens to assist in the analysis. The basic codes and master themes emerged as the interviews were conducted, and as more interviews were completed, these codes and themes changed and expanded. Large A3 paper was used to draw lines between codes or to circle specific codes together to visualize the relationship between the codes. This process was repeated several times as new relationships between concepts emerged and the strengths and weaknesses of some of the codes became more complex.

3.7.4 Evaluating the quality of qualitative research

The researcher investigated ways to ensure the quality of the research. Many of the methods described in the literature required the participants’ involvement, and since the study participants were older Saudi men and women, they were not very willing to read or sign the information sheet and consent form. Furthermore, some of the participants were illiterate. Therefore, it was expected that the participants who agreed to participate in this step would do so only as a formality and would not volunteer to contradict or add any information. Therefore, the researcher followed the 15-point checklist criteria below for good thematic analysis instead (Braun and Clarke, 2013)

Table 5 Checklist for good thematic analysis

Process	No	Criteria
Transcription	1	The data have been transcribed to an appropriate level of detail
Coding	2	Each item has been given equal attention in the coding process
	3	The coding process has been thorough, inclusive, and comprehensive
	4	All relevant extracts for each theme have been collated

	5	Themes have been checked against one another and against the original data set
	6	Themes are internally coherent, consistent and distinctive
Analysis	7	Data have been analysed, interpreted, and made sense of
	8	The analysis and the data match one another
	9	The analysis tells a convincing and well-organized story about the data and the topic
	10	A good balance between analytic narrative and illustrative extracts is provided
Overall	11	Enough time has been allocated to complete all phases of the analysis adequately
Written report	12	The assumptions about and the specific approach to the thematic analysis are clearly explicated
	13	There is a good fit between what the researcher claims to do and what he/she shows he/she has done
	14	The language and concepts used in the report are consistent with the epistemological position of the analysis
	15	The researcher is positioned as active in the research process (i.e. themes do not just emerge)

Qualitative studies generally require demonstration of the legitimacy of the research process which is achieved by rigour (Tobin and Begley, 2004). Trustworthiness can be achieved in many ways in qualitative research, specifically through the processes of establishing credibility, transferability, dependability, and confirmability (Lincoln and Guba, 1985). Credibility refers to whether the participants' view is represented by the researcher (Tobin and Begley, 2004). There were a number of strategies used in this study to address this issue such as prolonged engagement, peer debriefing, persistent observation, and audit trails (Lincoln, 1995). For example, the prolonged time that the research required to learn about the phenomena was years. With an adequate amount of time, extensive listening, transcribing, and reading more subtlety and meaning could be extracted from the interviews as more time

with the data meant deeper understanding of meanings. The continual meetings with the supervisory team through skype during the data collection fieldwork and face-to-face during the times the researcher was in Newcastle and analysing the data provided a peer debriefing strategy. The supervisors of this project came from different disciplines with extensive experience with this type of research. An audit trail existed as the interviews were coded and analysed.

Other ways to achieve trustworthiness are by addressing the issue of transformability. Transformability determines whether the results of the study can be transferable to other groups of people and contexts (Braun and Clarke, 2013). As Braun and Clarke point out, “the key to enhancing transformability of a study is to describe the specific context, participants, settings, and circumstances of the study in detail so that the reader can evaluate the potential for applying the results to other contexts or participants” (Braun and Clarke, 2013, p. 282). The detailed descriptions of the participants allow for other studies to determine whether their findings are comparable.

To maximise the use of the researcher as a tool, a reflexive process was employed. This involved maintaining a fieldwork notebook of observations, nonverbal cues that the participants gave as well as anything that required documentation during the interviews. Additionally, a reflective journal was kept in which notes on interview skills and issues faced during the interviews were recorded as well as emotional responses to the interviews. This journal helped in the reflexive and reflective process, which occurred during data collection as part of validating the interpretation of the participants’ accounts. It allowed critical examination of the methods during the interviews to allow for flexibility in asking the questions while still maintaining the direction of the research aims and objectives.

3.8 Ethical Review and Approval

The protocol of this research was submitted for ethical approval to the Newcastle University research ethics committee. Following the initial review, the committee was concerned that some of the participants who were not aware that they had Parkinson’s might (after the interviews) search the Internet for more information and subsequently discover their diagnosis. The committee was concerned about how the researcher would handle (or, preferably, avoid) this situation. This concern was addressed through clarification that all participants were being followed by the neurology clinic, and they therefore already knew they had a neurological problem. Furthermore, they were past the diagnostic stage; therefore,

each participant (or his/her family) had already received a diagnosis from a doctor.

Additionally, there were a description of steps that I as the primary researcher would take if and when the participants asked about their diagnosis. The fact that I am a qualified speech and language therapist and used to handling situations like the ones in this study helped the committee decide that the research protected human subjects. I also gained approval from the Internal Review Board of each of the data collection centres. See appendix G for a copy of Newcastle University Ethical approval

Each participant went through a consent process in which the study was explained, including steps to ensure confidentiality, the participant's right to withdraw, consent form signing, and information sheet explaining. The time and location of the interview were also agreed on during this process.

The researcher developed an information sheet that explained in detail the research being done, the aims, the process of the interviews and any information that the potential participant might need to know. The information sheet also included contact information for further questions and information on what would happen if a participant chose to leave the study. Two versions of the information sheet were developed: one for the person with Parkinson's and the other for the carer. The information sheets were developed in English, according to Newcastle University ethics regulations, and later translated into Arabic. Please see appendices H and I for a copy of the information sheet for both the person with Parkinson's and the carer. And appendices J and K for copies of consent forms.

Neither the consent form nor the information sheet for the person with Parkinson's used the word "Parkinson's", since it was possible that not all participants knew that they had Parkinson's. Instead, the phrase used was "swallowing changes for people visiting the neurology clinic". If a patient's family and/or medical team had decided to conceal this information from him/her, this decision was respected throughout the research process.

3.9 Conclusion

This chapter gives a description on the philosophical assumptions that I hold and that formed the basis for the design of the study and the selection of the data collection methods.

Although the location of the research is in a country far from where I live, face-to-face interviews and focus group were still considered and I had to travel a few times to collect the data. This restricted the traditional way of qualitative research but it still allowed me to immerse myself in the data and the times that were between the data collection trips were

used for more advanced data analysis. This also allowed for a prolonged time of data collection and data analysis giving me more time to reflect on the data and also the skills I was developing in my interview. All this allowed for a more detailed and rich data to be gathered and more time for a deeper analysis to be done.

Chapter 4. Findings

This chapter presents the findings of the study. The impact that eating change has on people with Parkinson's and the carers and families of people with Parkinson's will be further explored, particularly with reference to the religious and cultural contexts in which these changes are situated. It is organized to show how the findings of the first interviews were formative for conducting subsequent interviews.

The first part describes the findings of the initial data collection fieldwork, which included the first four interviews with participants with Parkinson's, the first two interviews with participants who were carers, and the focus group with the SLTs. The second part includes the findings of the interviews conducted during subsequent data collection fieldwork, which were interviews 5 to 21 of participants with Parkinson's and 3 to 18 of participants who were carers. The chapter sequence shows the iterative process the study went through, from a broad examination of the subject under study in the first data collection visit to an examination with more depth in the following data collection visits. This organization will show how the initial interviews informed subsequent interviews, specifically the reasons for the change of the phrase "swallowing changes/difficulties" in interview questions to "eating and drinking changes".

The interviews were planned based on the literature review to include questions about experiences of changes in eating and drinking, the impact of these experiences on various levels (i.e., emotional, psychological, and social), and the presence or absence of cultural and religious influence. Although in the interviews, the participants were encouraged to talk for themselves, the researcher controlled the discussion to prompt deeper insight into the description of experiences. The concepts of religion and culture were a thematic thread throughout the findings as they were almost always present in the answers of the participants. This is because the research question targeted the impact of a functional change on a group of people who belong to a particular culture/religion. Hence, the influence of cultural and religious concepts can be expected to be present in almost all the themes that will be discussed. As will be argued, based on the preliminary and in-depth analyses, the findings tell a story of people in a culture who are attempting to deal with eating and drinking changes while still maintaining social norms. Their stories tell of competing commitments and reveal assumptions about rehabilitation, medical treatment, and aging that could be viewed as unique to this particular culture.

In the next sections, I will present the themes that emerged, accompanied by quotes from the interviewees showing how participants expressed their thoughts and feelings about the changes in their eating and drinking habits. To do this, it is necessary to introduce the participants of this study. Creswell (2012) pointed out the importance of including the background of the participants, where they live and work, in order to understand the cultural setting of the study (Creswell, 2012). As mentioned in chapter 3, I interviewed 21 people who had Parkinson's as well as 18 of their carers. The basic information of the participants with Parkinson's such as gender, age, duration, and severity of the disease as well as the carer's basic information were all presented in chapter 3. The SLTs group will not be included in this detailed part, as their participation was used solely to add breadth of perspective when establishing the issues that people with Parkinson's and their carers might experience due to the swallowing problems that people with Parkinson's experience.

4.1 Findings from first stage of fieldwork

As was described in chapter 3, the first data collection trip was from May to October 2013. Although it was the longest data collection trip, it had the smallest number of participants due to the challenges discussed in chapter 3. The preliminary data from this stage were used to enhance the topic guide and interviewer skills to improve the quality and depth of the subsequent interviews.

4.1.1 Eating and drinking changes Vs swallowing changes

In the first data collection trip, there were interviews with 4 people with Parkinson's (2 males and 2 females), who will be referred to as Saleh, Housa, Noura, and Naif. Three of the participants had been referred to Swallowing clinic and were being seen by a SLT for their swallowing issues, while one was not referred to a SLT. Table 3 details the participants' information.

A major theme that emerged from these initial interviews was that the difficulties people with Parkinson's experience are more complex than the swallowing mechanism by itself. The interviews usually started with questions about swallowing difficulties that the participants had, but during the course of the interview and when the discussion moved to issues that they find challenging in their life, a fuller account of the eating process was revealed. In the interview schedule of this data collection trip, one of the initial questions was "Talk to me about your swallowing problem/difficulties/issues" these answers were from three of the four people with Parkinson's interviewed:

Hussa: *Alhamdulillah (Thanks to Allah), it's fine.*

Naif: *I can swallow, but not everything.*

Noura: *There is a problem here (point at throat) but I don't know... Ask my daughter.*

During the course of the interviews and while the interviewer was discussing issues about life, health, and family, the following quotes appeared from the same three participants:

Hussa: *It [eating] bothers me.*

Naif: *I fear eating.*

Noura: *I don't enjoy eating.*

This seemed to reflect a difference in the way they perceived the difficulties that they have compared to those described in the literature. When the words 'eating' or 'drinking' were used in the interview questions, the participants gave different accounts than when the phrase 'swallowing changes' was used. Considering that the person who said '*it's [swallowing] fine,*' later said '*It [eating] bothers me,*' there seemed to be a disconnect between discussing the process of swallowing and the process of eating. Swallowing was not the issue that the participants with Parkinson's identified with. Instead, participants' answers indicated a need to address the whole eating process because the technical term 'swallowing' did not elicit the same responses as the whole eating process. By changing the focus to eating and the context of eating, the questions matched the broader view of issues that affect the person due to his/her difficulties in eating.

The latter three statements opened a new area to explore: how a known socially pleasurable activity is being described as feared and not enjoyable. When the issue of eating difficulties was explored further, one of the participants with Parkinson's gave more detail:

Noura: *I can't sit and eat with my family.... I have to eat with her (pointing at daughter).... No they [the family] eat somewhere else.*

Hussa similarly stated:

We eat together but I have my food... I don't eat their food.... I am diabetic.... I can't chew meat.... Rice and soup...because they are easier for me.

Hussa, who previously gave examples of the food she cannot eat, described what she does when she is invited to social events:

I stay in my son's house... it is better.

When prompted to elaborate she admitted:

It is easier for me to stay.

She did not give any additional explanation at this time. Later in the interview during more informal conversation about how weddings nowadays are changing and not as traditional as in the past, she stated:

I don't like to eat in front of people.

Although she did not elaborate further on this topic, the statements that she made might be linked. She reported eating different food than her family, she said she preferred to stay home when she is invited, and she stated that she does not like to eat in front of other people. This is important to consider because the traditional and common meal that Saudis eat in both home and at social events is Kabsa (rice cooked with meat or chicken), and she had already identified that she cannot eat rice or meat. This restriction might make her self-conscious to eat in front of others at social events. This indicates both a restriction in social life as well as a feeling of embarrassment due to her difficulty in eating.

It is also important to mention that this statement '*I don't like to eat in front of people*' was not made when asking a direct question that related to social life and changes to eating, but instead was made when the discussion was lighter and the question was not direct. It was when the interview context became more like a couple of women chatting about the wrong things that can happen at weddings that the participant with Parkinson's expressed her anxiety about eating in public. This provided insight into how to conduct the interview to explore the topic further.

In another interview and while asking Naif about how these eating changes affected his life, he said:

I don't go to weddings...It's difficult... the food in the wedding is not easy for me to eat.

Naif identified weddings as the events that were affected by his eating changes. This disclosure indicates the effect of these eating changes on his social life. Identifying weddings as an example that he gave when asked about his social life also indicates the significance of this event in the Saudi culture. Weddings are important events in Saudi Arabia. They are

predominantly large events that all relatives attend, and older people are usually considered hosts at weddings. As hosts, they sit at a place of honour where guests come and congratulate them, even if they were not parents or grandparents of the couple. During the meal, the older relatives are usually the first to sit, and they have a place of honour on the mat that they would eat on.

Further evidence that the impact of difficulty swallowing (coughing) was not only physical but also psychological, was provided by Saleh, who was the only one interviewed that was not referred to a SLT. While there was no information in his file that he complained of any swallowing difficulties, he stated in his interview,

I cough with water.

And later said,

It's embarrassing... the coughing (pointing at throat).

Although this person with Parkinson's had not been seen by a SLT and did not complain of a swallowing problem, he indicated that he had a swallowing problem when he pointed that his cough comes with drinking. This statement led to changes in the recruitment criteria concerning using the word 'swallowing' because it seemed that the participants with Parkinson's did not interpret their coughing as a problem with swallowing. In addition, it was other people's reaction to this change that this person with Parkinson's was most concerned with. More detail on how this informed recruitment will be discussed later in this section.

Some questions about Parkinson's in particular shed light on part of the underlying problem. In trying to understand how people with Parkinson's experienced changes in swallowing as result of their Parkinson's, the interviews revealed that some of the participants with Parkinson's did not understand that Parkinson's was a disorder that affected multiple parts of the body but instead thought that the symptoms they experienced were just a part of old age. Naif showed this when he referred to just one symptom as Parkinson's.

Naif: It [Parkinson's] is this (showing his hand)... Look... it shakes... that's it.

Later, he said:

With age... everything becomes damaged (smiling) like an old car... you're walking, then you're sleeping... then you're eating... one day nothing works...we say Alhamdulillah.¹

These two quotes show that he identified Parkinson's as the motor symptom of his hand shaking, but he did not mention any of the other symptoms as part of the disease. Later in the interview, he mentioned the other symptoms (walking problems, difficulties with sleeping and eating) as signs of old age and not Parkinson's. This, as well as comments from the other participants, provided the insight that some participants with Parkinson's had limited information on Parkinson's, and informed a line of inquiry into what information is provided to patients about their diagnosis.

Noura, who has been diagnosed with Parkinson's for 12 years, did not know she had Parkinson's, and her son (not her carer but the person I talked to when introducing the research and asking for their participation) informed me that his mother is unaware that she has Parkinson's and that the family preferred that she did not know. When I asked him to explain how this was possible for the last 12 years, he explained that the diagnosis was given to him by the neurologist, and that they come to the neurologist every few months for a follow-up and a prescription for medication. Noura knows that this medication helps her with her tremors as well as help her sleep and relaxes her muscles, as the son described.

In the interview I had to be careful with the questions to avoid mentioning Parkinson's to her. When I asked why she was here in the clinic, she said:

The doctor gives me medication... medication to help me.

When prompted about her illness, she said:

I don't know ... You can ask the doctor.

And when asked what she thought was causing her to cough and make her eat different foods, her reply was:

I am an old woman... I don't know these things.

These parts of the interview confirm that Noura does not know she has Parkinson's but also indicate that she might not be interested in this knowledge or might think it is not her role to ask questions about her health. They also provided evidence that the data collected in future

¹ "Thanks to Allah."

interviews would be strengthened by asking more questions about the participants' life and family to try to understand how a woman from Saudi Arabia with Parkinson's deals with the changes that happen as a result of Parkinson's, especially with regard to eating and drinking. It also shows an example of the brevity of answers given, with minimum elaboration even when prompted. This type of response was common in most of the interviews with the participants with Parkinson's, which will be discussed in chapter 5.

4.1.2 Carers interviews (family and social lives)

When the carers were asked about the impact that Parkinson's had on their parents, their answers were more descriptive and had more details when compared to the interviews with the participants with Parkinson's. Reem, the carer of Noura, who has been diagnosed for 12 years but is unaware of her diagnosis, said:

It is hard on her... she used to be a strong woman... now we have to help her.... in many things: dressing her, feeding her, and even taking her to the toilet.

When I asked about the impact of this on her mother, she replied:

She is suffering... and it is getting worse... she is in pain, and she can't walk now anymore... she has to be cleaned and carried to her bed... You know, this medication now doesn't help her like before. She now suffers a lot. May Allah help her.

She later explained, when I asked about what she as a carer does to help her mother,

I help her with eating... it is one of the things I help her with... my sisters also help... we make sure she is clean... we help her dress, wash, and go to bed.

When the researcher asked the carer about what she does to help her mother during mealtime, the carer answered,

I put her food on a tray and bring it to her wheelchair... we have a table like the one here [pointing at a hospital table that has the height adjustable] and she can eat from it... I make sure the food is soft and I stay with her when she is eating... I need to hand her a spoon and sometimes I need to feed her with my own hand.

When asked about her mother's social life, the carer said,

She doesn't like to go out, but I think it is because of her wheelchair. She doesn't want to be carried. She knows it is difficult for all of us to carry her...

Later in the interview, she said,

We [the daughters] also stopped going out... you know, you have to have your mother with you.

Reem described how her mother is struggling with the changes that she goes through due to her Parkinson's. She explained the carer burden in detail, giving descriptions of her role in helping her mother during mealtimes and other ways in which she has to help her mother with different activities due to the symptoms of Parkinson's. She mentioned that this role is shared by other members of the family, specifically sisters. Her responses show that she acknowledged that her social life is affected by her mother's Parkinson's. She does not attribute her reason for staying home to having to stay home to care for her but instead says that it is because she cannot go out without her.

This conversation shed light on two underlying concepts that are important for this population. The first is the diversity in Saudi cultures. In this case, this carer comes from a culture where it is not acceptable for an unmarried woman to attend certain events without her mother. This gives insight into how Parkinson's changes would be different for various carers according to the Saudi Arabian culture. The second concept is how the country is not accessible to those with disabilities or those who use wheelchairs. This has a unique impact on the social lives of both people with Parkinson's and their families.

Although earlier she was very descriptive in her discussion about the struggles that her mother goes through and identified a change in her own social life, when asked directly to identify the impact of the changes on herself, she was reluctant to identify changes. When this daughter was asked about her life and the impact of her mother's disease on herself, she answered,

Alhamdulillah... there is nothing to do about it.

When asked directly, 'talk to me about the changes in your life since your mother began depending on you to eat' she said,

I don't know what to say... Alhamdulillah.... Nothing changed... we still live our lives... Alhamdulillah

There are a number of possible reasons for this. The way the question was phrased or the person the question focused on may have elicited different answers. It may be that this carer differentiates between the impact of the changes on her social life and the impact on her life. Although her social life changed, it changed in a way that is culturally acceptable, and her

acceptance of the change may be reflected in her responses. Or, the daughter might not have previously reflected on how her mother's Parkinson's and her cultural/religious rules affected her. Perhaps, the daughter was simply uncomfortable stating aloud the impact her mother's disease had on her in a medical office or it may be unacceptable to acknowledge caregiving as a burden because it is expected of certain individuals. This might be why she used the phrase Alhamdulillah three times in this section. These phrases might indicate that her religious beliefs could be a barrier to her stating the effect her mother's Parkinson's has on her. Or, the repeating of this phrase could indicate that she feels that the changes are out of her control and are in the hands of Allah. If this is the case, she may feel like her only option is to persevere. All these possibilities needed to be considered when planning the topic guide for the future interviews because it was evident that answers (and questions) were culturally bound.

Waleed, who is the carer of his 71-year-old father who knows that he has Parkinson's and is being seen by the SLT at the swallowing clinic, explained,

He has to have his food cooked for him because he (name of SLT at swallowing clinic) told us he cannot eat hard food... he has to eat soft food.

Later, he said,

I think that's why he lost weight... maybe the food is not nice... I am not sure...

Then, even later, he said,

He has a problem with swallowing food... he coughs with his food...

While trying to understand the issues his father has with his swallowing, the son elaborated,

The way he eats changed... it is not like before... I don't know how I can explain it... you can ask him (name of SLT at swallowing clinic). He will tell you.

These responses show that although this carer understood that his father has problems with his swallowing, he had difficulty expressing what those problems were or did not feel qualified to describe them correctly hence asking the interviewer to ask the SLT. It also showed that the interview needed to include different questions and more prompts to allow participants to express the issues with swallowing and eating in more detail. This informed interview questions in later visits by changing the questions to focus on describing the food that the person with Parkinson's can or cannot eat so as to elicit more discussion on why these types of food are allowed or not. Questions were further expanded to ask carers to describe the

typical family meal and what differences there are with this compared to a few years before or prior to their family member having Parkinson's.

In a later part of the interview, this carer said,

We do face problems going out. It is not easy on him eating when we visit our relatives... I think he feels uncomfortable when he is not eating in his usual way.

This response showed the need for future interviews to include more questions about eating with relatives. This builds on the responses from Hussa and Naif about attending weddings and eating in front of other people. Because eating with relatives is very common in Saudi Arabia and is part of the social life of the Saudi family, it is important to examine various eating contexts and to always ask about eating and other activities with relatives.

Another important learning opportunity from this interview was that although this person with Parkinson's had eating difficulties, he still visited relatives. This begged the question of whether relatives are next door or require long distances to visit. One way to address this is to acknowledge that when referring to relatives, there may be diversity in who is included in that group. Future interviews, therefore, needed to include a focus on details about who the word "relatives" refers to and what these visits entail.

Similar to the responses of Reem, when asked about the impact on his life due to his father's swallowing problems, he explained,

I don't know... I don't think anything changed... my life is the same.

He later elaborated,

Of course there are now changes in our lives... my father now is ill and he needs help so our lives change... we don't do the same things we use to do... but it is expected... no one's life stay as it is.

Initially, when asked, Waleed stated that his life is much the same. However, after talking more and with more prompts, he acknowledged changes to his and his family's life but did not elaborate on it. These responses indicated a need for a change in the way questions were asked. It was unclear whether responses changed throughout the interview because of the establishment of rapport or whether there really are differences in the way carers think about the impact of their parent's changes on their own lives. To address this, future interviews needed to include more time for building rapport, more time and different ways of asking

about the changes to help respondents reflect on the changes that happened. Asking about their food, their mealtime, and their social life in general would allow the participants to think about these topics and give examples or details on the impact on their lives.

4.1.3 Findings from SLTs focus group

In this section, the results of the focus group with the SLTs will be reviewed. The three SLTs discussed their views about the swallowing problems faced by people with Parkinson's, issues and challenges that SLTs face in management of these difficulties, and their patients' compliance with their treatment programmes. As a reminder, the three SLTs had all been working for a minimum of three years with people with Parkinson's in the Communication and Swallowing Disorders department at KFMC. The focus group discussion was guided by the focus group topic guide (see appendix A) but allowed for the participants to freely converse with each other when discussing the questions.

At the beginning of the focus group, the SLTs acted politely, with each looking at the other to start answering. They seemed to be hesitant to start the conversation. This was also evident in the joking manner with which they suggested that the eldest should start providing the answers. This joking then led to ease in the conversation and more general discussion about their work with this specific population. Later, there were more focused questions about areas that are most challenging to them when dealing with swallowing difficulties in people with Parkinson's.

The questions were guided by the SLTs own answers about the behaviours and attitudes of their clients toward rehabilitation and SLT services. The answers generated more questions to explore the important influence of the Saudi culture and Islamic religion. In this part of the focus group, the discussion became more relaxed, and the SLTs were more eager to participate.

The first challenge the SLTs mentioned when asked about the difficulties they face working with people with Parkinson's was compliance with recommended treatment. The SLTs agreed that the majority of their clients with Parkinson's do not show up after the first session and are not interested in rehabilitation. When asked to elaborate, the SLTs said:

F: They just don't show up.

S: They come for the first session. They actually don't miss this one, but the following session they don't show up.

F: *They saw us (laughing).*

K: *Yes, it's true! They saw what we do, and they didn't like it.*

It became apparent that the low compliance of people with Parkinson's happened after the assessment session (the initial session). Part of the assessment protocol is that the SLT explains the rehabilitation plan to the patient. The SLTs' responses indicate that they perceive patients as not being interested in or not liking the idea of the recommended treatment plan, which includes multiple visits. It might be that people with Parkinson's do not feel that this plan or type of treatment is beneficial to them or it could be, as K said, that what happened during that initial session caused the patients' reluctance to come back. These are areas that required future explication in interviews with people with Parkinson's and their carers.

This led to a discussion of the services the SLTs provide and their perceptions about why patients might not like it. One reason they mentioned is that the services provided by the SLTs are not the conventional medical services that the patients are used to.

F: *I would get a patient coming and then [say] "that's it? There are no pills?"*

K: *"That's all you have?" "So these pictures and nothing else?" and a lot of the times "there is no medication?!"*

F: *They make me feel that I have to do something... physically in the oral area.*

S: *They just don't understand rehabilitation.*

The SLT's presumed that it is the nature of speech and language/swallowing sessions that cause the patients not to show up. These sessions depend on training or exercises performed by the patients as demonstrated by the SLT, which are very different from the interaction that this patient would have with his or her doctor. This also may point to a difference in the clients' understanding of treatment as a cure that is provided externally versus something that has to be practiced and worked on. The final comment in the above list shows that there may be an issue with clients understanding or believing in the concept of rehabilitation.

F provided insight into another reason why people with Parkinson's might not want to attend SLT sessions when he said,

This is something that reminds him [a person with Parkinson's] of his weakness. And also, when he reached a certain rank [family/tribe position] in the society, even if this rank is not high from a vocation point of view, but high on the family level, that means

he has lots of grandchildren and so on, sons and in-laws, and then he goes to a place where he must be taught how to do basic things. It is not acceptable to him.

A patient's position as the father or grandfather in the family might be an obstacle for accepting the role required of them in a rehabilitation programme. As F called it, 'basic things' that the patient needs to relearn might cause him to feel offended or uncomfortable.

Another issue that was discussed was how people with Parkinson's understood their problem of swallowing. This led to a discussion of issues about the knowledge and awareness of their clients with Parkinson's.

K: They are here because a doctor referred them. Not because they ask for us.

F: They don't know what it means to have dysphagia.

S: Yes, a lot of people don't know it [dysphagia].

F: It is the understanding. They don't understand what it means to have Parkinson's. [I] don't think they recognize the symptoms.

K: Some of them think it's old age.

F: Yes, old age and you know it is things that they can deal with. You know, it is not life threatening so why bother... Overall, our patients are not concerned with knowing the names of diseases. You talk to them about something, and they listen. They don't ask questions. They are not curious.

These quotes show that the SLTs perceived this population as having a limited knowledge of Parkinson's and the symptoms that they experience due to this disease. Although it is not clear why this is the case, this was important information for further exploration in interviews.

When the SLTs returned to discussing compliance of people with Parkinson's to their sessions, they mentioned the role of other family members in the lives of their clients.

F: For example, I had one patient. He was extremely old, multiple medical conditions, and Parkinson's. I didn't feel he was up for any therapy programme... but the family kept on nagging on the subject [therapy] because they... what they are doing is part of albir. [they say] "There is a service and we have to make sure he [father] will take it."

In this quote, F indicated that the reason these patients show up is because their children require it; it is the children's sense of obligation that drives them to bring their parents to the sessions. This obligation is an Islamic concept of *albir*, which is the expected way for a person to treat their parents. In another reference to *albir*, F told a story of a patient he had from outside of the city. He described how persistent his client's son was in coming to the clinic, despite the long distance from their home and the fact that the patient was not willing to come and the outcome of the sessions was poor.

One SLT described another important aspect of *albir* and its relationship to rehabilitation compliance. S said,

Please, I want to comment on albir, for me I sometimes see it differently. Sometimes I,... like this patient I had, her daughter says "it is difficult for me to be in the other room, and she [her mother] is calling me but I don't answer her until she raises her voice, as part of the training". So, it is difficult for her to hear her mother and not answer. She said she feels like she is committing a sin.

S was describing a patient with a voice problem, and indicated that the Islamic beliefs of the daughter cause her to reject the training and go to her mother. She would not follow the SLT's instruction to wait until her mother had raised her voice to answer, because she felt she had to answer right away. In the daughter's mind, the recommended action for rehabilitation is in conflict with her beliefs about her role as a daughter in Muslim culture.

These quotes give great deal of information about the way the participants with Parkinson's reacted to the rehabilitation programme and the role of their children in their lives. They show that although the literature discusses how dysphagia impacts the lives of people with Parkinson's, these SLTs think that the people with Parkinson's were not interested or willing to work with them to improve their swallowing abilities. They also show the complexity of the effects of family dynamics on compliance. They attribute noncompliance to sons and daughters feeling obligated by their Islamic upbringing to help their parents as much as they can, even if it is in opposition to recommendations by SLTs. It may also show that as parents, the people with Parkinson's may comply with the therapy programme only for the sake of their children, even when they are not interested in working with therapists.

It may be that people with Parkinson's and carers do not see the therapist as helping but instead see them as recommending something they do not agree with or as not helping because they are not curing Parkinson's. Although old age is seen as body deterioration in

some cultures, it may be that the perspective of old age in Saudi culture is seen as normal and body changes are just part of taking on a new honoured role. It sounds like they are accepting that these changes are different for all people and theirs are not special.

When asked about the challenges their Parkinson's patients deal with when they come to the clinic, they mentioned the swallowing assessment.

K: The patients don't like the food we give them for the assessment... We add a powder to thicken-up the food and drinks until they reach the consistencies that we want before we do the VFS.²

S: The assessment is strange. You know, you are in the X-ray department, and you are wearing that big protection shield and eating from a spoon or a fork.

K: (smiling) When I dip the piece of toast into the Barium, they ask me "what is that?" I used to say "bread" and they would look at me strangely. Now I say "material for the x-ray", and they eat it.

S: I found out that some of our patients never had toast before.

In many regions of Saudi Arabia, a spoon is only used for eating soup, and no one uses forks. Thus, the items in the dysphagia assessment tray were not all familiar to the patient, including toast. These comments also show that when the SLT stopped referring to toast as bread and indicated that it was a material used for the imaging assessment, the patient was more willing to eat it. Another quote from K shows similar references to food:

I had once a patient who had dentures. He told me he was eating regular diet at home, so I presented him with cucumber from the food options on the tray... I gave him cucumber because he has a regular diet, at first he held it like this (making a hand gesture like a fist), I was surprised he didn't eat it, but was looking at it, as if he was thinking of something then he looked embarrassed and he put it in his mouth... Then later when we were talking I asked him "what's the problem? Why were you looking at the cucumber?" And he said, "I don't eat the cucumber like this. You know, big pieces. I don't eat it because it goes under my dentures." But he was too polite to tell me.

² Videofluoroscopic swallowing study. A procedure used by SLT to assess patient's swallowing. The patient swallow a variety of different liquids while the radiologist take a number of video X-ray images.

The patient in this case chose to eat a difficult food for him because he was not comfortable telling the SLT that he could not eat it what was offered to him. He was treating this session as a social visit and did not want to offend the SLT by rejecting the food he was being offered. If K had not asked, he would not have known that this person had difficulties with this type of food. This sheds light on another issue that SLTs face, which is the way Saudi patients, especially the older generation, interact with people who work in hospitals or perceive and act in these sessions. The SLTs reported that their patients are often overly polite and act as if they are imposing on the medical team by seeking treatment. They typically express extreme gratitude, and they act as if the medical team is doing them a favour. It is important to bring this issue to light as it may also illustrate how people with Parkinson's in Saudi Arabia access and seek health services and how this in turn will add to the impact of Parkinson's on them and their families.

4.1.4 Reflecting on the first stage of fieldwork

Although this data collection phase had a very limited number of interviews, it provided insight into the most effect means for collecting data for this study. It also provided valuable preliminary data that guided future interviews and led to the use of interview techniques that provided more depth and details of the experiences of these people with Parkinson's and their carers.

One important finding of the initial interviews was that the terms 'dysphagia', 'swallowing', and 'swallowing problems' are not words that the participants relate to when discussing the impact and experiences they go through because of their dysphagia. These words are limited in their ability to express what the people with Parkinson's and their carers experience.

Therefore, future interviews referred to these issues as eating and drinking changes, resulting in more detailed responses. This change seemed to allow participants to reflect on the whole process of eating and drinking including the contents as well as the context of meals.

As for the interviews with both people with Parkinson's and carers, there was a noticeable difference between the responses. Although only four people with Parkinson's were interviewed and only two carers, more codes and themes were extracted from the carer's interview than the interviews with people with Parkinson's. The interviews with the people with Parkinson's were shorter, with single sentence answers, and a great deal of prompting required. The carer interviews were longer and involved detailed answers with minimal prompts. This finding indicated the need to change the interview protocol for people with Parkinson's interviews to get more details. While the carer interviews were an important

source of information in their own right, they also served as a supplement to the data collected from the participants with Parkinson's.

A challenge to interviewing one of the participants with Parkinson's was interviewing about the symptoms of Parkinson's without discussing Parkinson's, as the patient did not know she had Parkinson's. It was a situation in which the researcher did not have the authority to inform the participant that she had Parkinson's and the family's choice to not inform the participant had to be respected. This incident provided one example of information sharing that might be a challenge to collecting data on any medical condition. Researchers need to be aware that they have assumptions about what information has been provided and to be prepared for this possibility with regard to information sharing.

During the focus group, the SLTs discussed the topic guide at length, but the discussion was diverted to the differences between assessment/treatment programmes in the Saudi context and what research literature says is the appropriate treatment. They discussed their concerns with the rules of Saudi culture and Islamic religion, particularly how they affect the way people deal with health problems, the way they deal with health care workers, and their level of acceptance and understanding of medical intervention and rehabilitation services. They also discussed the patients' and their families' understanding of Parkinson's and the changes in swallowing that are associated with the condition. Finally, they discussed how the families were coping with these changes.

When the group discussed the influence of Islamic beliefs on the way their patients deal with their disorders, they specifically referred to the issues of *Qadar*³ and *Albir*⁴, although they used these two terms interchangeably. This is similar to a study that also examined the effects of Islam on attitudes toward rehabilitation and found that the Muslim patients have a belief that God has absolute control over their lives including recovery from illness (Yamey and Greenwood, 2004), which the SLTs expressed as *Qadar*.

Using the focus group method for data collection allowed for identification of not only new ideas for the interview topic guide, but also identified perspectives shared among all or most of the SLTs. As Litosseliti (2003) discussed, focus groups allow for shared understanding of a specific topic while generating new ideas (Litosseliti, 2003). This was important at this early

³ *Qadar* (Predestination), an Islamic concept of divine destiny.

⁴ *Albir* is an Islamic concept which guide how a person should treat their parents.

stage of the research as it allowed for the SLTs to build on the statements of the other SLTs to express their views on their experiences working with people with Parkinson's.

The following is a list of preliminary themes that emerged from these initial interviews and the focus group of this first data collection trip. These themes were used to guide subsequent interviews to extract data with both breadth and depth.

Challenges SLTs face when working with people with Parkinson's
Knowledge and awareness of people with Parkinson's and their carers about Parkinson's
Knowledge and awareness of people with Parkinson's about the changes that have occurred in their eating and drinking
Impact of eating and drinking changes on the social and familial life of people with Parkinson's
Impact of eating and drinking changes on the social and familial life of carers
Role of culture and religion on people with Parkinson's and carers when coping with changes to eating and drinking
Influence of Saudi culture on medical treatment and rehabilitation

4.2 The Study Themes

In the second and third data collection phases, interviews were conducted with 17 people with Parkinson's and 16 carers. These interviews were based on a more refined and detailed interview protocol (Appendices C and E) based on the previous data collection trip, which led to higher quality data with more breadth and depth.

In addition to using the initial interviews and focus group to refine the data collection process, an iterative process was used to analyse each individual interview. Specifically, after each interview was conducted, researcher insights and reflections were used to develop preliminary themes and areas that needed expansion in subsequent interviews. This led to the development of a list of emerging themes that were later categorized into master themes based on the relationships between them. The following sections detail these themes and subthemes.

The changes to eating and drinking were numerous. Some were those that all people with Parkinson's and their carers might experience regardless of cultural background, and some were quite specific to the culture. Therefore, the findings will be presented first on

experiences that were expressed by the people with Parkinson’s and their families that can be labelled as “universal” and later on eating and drinking changes within the context of the situations in which Saudi citizens consume food. The three main themes (which are actual quotes from the interviews) and their subthemes are explained below.

The first theme is ‘the whole meal is awkward’ and focuses mainly on the people with Parkinson’s. This theme includes multiple dimensions. First, it involves the challenges that people with Parkinson’s go through due to their restricted eating and drinking abilities regardless of their country or culture, what can be called the universal eating and drinking changes. Second, it involves culture-bound challenges referring to the more cultural and situational issues surrounding eating and drinking changes. These are what the participants expressed as issues that are related specifically to the Saudi culture or cultures that are Arabic or Islamic. Third, it involves the emotional and social impact of these eating and drinking changes on the people with Parkinson’s (the impact on carers falls under the second major theme). Table 6 shows a list of the subthemes for this theme that will be explained in the following section.

Table 6 Theme 1

Theme 1		
The whole meal is awkward	Universal eating and drinking changes	Prolonged eating and drinking
		Fear of choking
		Restriction of types and consistencies of food
		Difficulty/inability to swallow pills (medication)
	Culture-bound eating and drinking changes	Having to use a spoon instead of one’s hand
		Having to sit at the table instead of on the floor
		Restriction from coffee
	Psychosocial impact on people with Parkinson’s	Isolation
		Embarrassment
		Uselessness

The second theme is ‘we all have Parkinson’s’, which was a statement from one of the carers. This theme involves subthemes that relate to the carer and family of the individual with Parkinson’s and again includes universal issues for families caring for a person with Parkinson’s as well as issues unique to the cultural response to changes in eating and drinking associated with Parkinson's. Because of social, religious, and cultural expectations and norms, certain aspects of dealing with the eating and drinking changes associated with Parkinson's were reported to be more challenging than others. Table 7 shows a list of the subthemes associated with this major theme.

Table 7 Theme 2

Theme 2		
We all have Parkinson’s	Carer experiences	Burden of care
		Carer’s social life
		Carer emotional involvement
	Family	
	Relatives (<i>Silat-ur-Rahim</i>)	

The third theme is ‘I leave it all to Allah’, which was a statement by one of the people with Parkinson’s. This theme involves all the issues that were perceived by the people with Parkinson’s or carer as beyond their control. These include cultural and religious themes as well as the country's health policies relating to SLT services for individuals with Parkinson’s. This theme also reveals assumptions and beliefs about health and health treatment that influence how changes in eating and drinking associated with Parkinson's are responded to by people with Parkinson’s and carers. Table 8 lists the subthemes for this major theme.

Table 8 Theme 3

Theme 3		
I leave it all to Allah	Cultural and Islamic barriers	<i>Ibtilla</i>
		Gender segregation
		Transportation
	Knowledge barriers	Understanding Parkinson's
		Health Service Organisations and Availability role

Parkinson's causes functional changes that hinder a person's ability to eat and drink normally; this leads to people finding themselves in situations where it is expected that they must eat with others. Such situations result in emotional themes that the people with Parkinson's and their families express in association with these situations. When considering the customs of eating and drinking within this culture, it was possible to see why these feelings were so intense.

We may also see how the interpretation of a person with Parkinson's of the eating changes they experience would affect their management of these changes. For example, their cultural background can delay them from receiving interventions that might reduce the effects of the changes. This highlights the necessity of examining how issues like Saudi Arabia's Islamic interpretations and the types and availability of the services offered to people with Parkinson's and their families can also affect how these changes are experienced. The findings show that it is the relationship between the themes that emerged in this study that provides the answer to the research question. The next section further considers the relationship between the themes in an effort to truly explore the experience of eating/drinking changes and their impact on person, family, and community.

4.3 Theme One: The Whole Meal is Awkward

This section reviews the experiences of people with Parkinson's that relate directly to their changes in eating and drinking. A type of experience will be called "universal" if any person with Parkinson's might experience it and "contextual" when it is directly related to the situation in which it occurred. The changes that were reported encompassed both physical aspects of the swallowing process and psychosocial reactions to these changes. Participants reported physiological changes and their effects such as tremors and swallowing resulting in prolonged eating time, fear of choking, restriction from certain food consistencies, and

difficulty in swallowing pills. These physiological changes had a social and situational impact on the eating and drinking routines of people with Parkinson's. Specifically, they were no longer able to eat on the floor and experienced challenges eating with their hands and a spoon. Carers expressed pity at seeing their loved one not being able to eat normally, and there were challenges to having the person with Parkinson's eat with the family or alone. The last part of this section describes the emotions expressed by the participants as the results of these experiences. Participants expressed feeling isolated, embarrassed, and not feeling useful in the household any longer.

4.3.1 Physiological eating and drinking changes and their effects

The main symptoms that the participants with Parkinson's complained of were motor symptoms: in particular, rigidity, tremors, and posture. Comments included *"My legs don't support me"*, *"I have to sit on this now (points at wheelchair)"*, and *"I need help with everything"*. In discussions about their mealtime, participants identified issues related to the process of eating and drinking.

One of the changes that people with Parkinson's experience is that the process of eating takes longer than they were used to. The following quotes show how the participants with Parkinson's and their carers felt about this increase in eating time. Ali, a male participant with Parkinson's who had had Parkinson's for over 17 years and has not been seen by a SLT, said,

I chew, chew, chew... I want [the bolus] to go down... I stay like this for a few minutes, and [the bolus] still does not go down.

While Mansoor, another male with Parkinson's who had had Parkinson's for 7 years and has also not been seen by a SLT said,

[Swallowing] is hard... I mean, I want to swallow, but I cannot... I mean (closing his eyes and putting his hand on his throat), I do this (pretending to swallow or to try to swallow)... It takes a long time before the swallow come[s].

Sameera, the daughter of a female with Parkinson's (Haya, who had been diagnosed with Parkinson's for 9 years and has also not been seen by a SLT) stated,

She takes longer because she has a problem with chewing food... She is not as strong as she used to be... Her chewing is weak... This makes her meals longer and longer.

All three of the people with Parkinson's quoted above were taking longer to complete their meals than they had in the past. Two of them related this difficulty to the process of chewing (longer, weaker) while the other (Ali) believed that his prolonged eating process was caused by his lack of a swallow reflex—he had to force himself to swallow. He said,

The food does not go down... When I swallow... [The food] stay[s] here (pointing at his checks).

When asked what he did when this happened, he replied,

I swallow again and again... Sometimes, I put my fingers here (inserts his finger inside his check), and I chew again and swallow... Sometimes, I drink water... I drink little water... It [water] takes it down... But sometimes, I choke on the water, and I go from one problem to another (laughs).

This participant with Parkinson's struggled with swallowing; this difficulty caused him to take longer to swallow a single bolus. This quote also indicates another difficulty that people with Parkinson's face when trying to eat and drink, which is the need to drink water to expedite the swallowing process. The drinking process presents a new challenge because it causes coughing, which is another swallowing difficulty. It is important to note here that the three people with Parkinson's who offered these quotes had not been seen by a SLT, even though their comments are significant swallowing complaints. Further investigation of the medical files of these participants revealed that they contained no notes that these dysphagia signs had been documented by any of the healthcare workers who had seen them. This is further addressed in the discussion chapter.

Hand control can also cause other eating challenges. In one interview, a carer (Raid, the son of Saad, a 57-year-old with Parkinson's for 3 years) explained that his father had become particular about the food he ate because of the way in which he had lost control of his hands. His father now avoided certain types of food, depending on his ability to eat them.

Raid: Wallah,⁵ *he struggles sometimes... especially when his [tremors] are high... then he struggles with eating with the spoon... sometimes he refuses to eat marag⁶ because he knows he will spill it all.*

⁵ *Wallah* is an Arabic expression meaning “By God”.

⁶ *Marag* is traditional Saudi soup.

INTERVIEWER: *Other than marag, does he struggle with anything else when the vibrations are severe?*

Raid: *The marag, because it is liquid, he has to hold it in a spoon, and when the vibrations are high, it is hard. But he eats everything else with his hand... He sometimes spills rice... but he is careful, you know ... If that day, his vibrations are high, he knows what to eat... I tell him, "Drink the marag from the bowl", "Don't use the spoon", but he doesn't like that... He feels he will look strange, you know... But, Alhamdulillah, he takes his medication at times, and these vibrations are not always high.*

Adel, the male carer for his father Ali, described his father's eating. When I asked what his father does when he cannot use the spoon, Adel said:

Tsk, tsk, miskeen (poor man), now we have to give him a cup to use... like a spoon for his soup. Alshakwalalah (we can only complain to Allah).

Although, in this case, Ali had found a technique that allowed him to keep drinking soup, the idea that he had to use a cup instead of a spoon appeared to be disturbing to the son; his answer started and ended with phrases indicating his pity at his father's misfortune.

Another man (Ahmed) also faced challenges due to hand tremors. In the following interview, the wife (Hailah) discussed how her husband waited for her to cut his food for him:

I feel sympathy for him. He needs me to cut his food; if I was busy and I didn't sit with him and cut his food, he would sit quietly until I came. He doesn't eat until I sit beside him. Sometimes I have to ask one of the boys to cut his food, but he doesn't ask [them] himself... He will sit still, waiting for me.

This statement also demonstrates the changes that occur when a person with Parkinson's needs help with eating and how this can impact both the people with Parkinson's and their family and carer. The carer's role here was not only to prepare meals for the person with Parkinson's but also to assist during meals, which added to her burden of care. Her account of him waiting for others to cut his food and sit with him may indicate dependency but also may show this man's preference to eat with his family.

Finally, the carer below (May) showed the linkage that the progress of the Parkinson's had on eating changes in her father (Mansoor):

At the beginning, no, he didn't have a problem... Alhamdulillah... he ate normally... He ate on the floor... and he got up and everything was normal; but, as I told you, the last six months... he's become worse... Now, the spoon reaches his mouth but not easily or smoothly.

Another type of experience that the participants with Parkinson's reported related to their safety while eating. The participants expressed their fear that they might choke on their food; they did not view eating as a safe process. One participant, Ibrahim, a stage 2 male with Parkinson's, had never seen a SLT, and nothing in his medical records indicated that he had a swallowing problem. When first asked if he had experienced any changes while eating, he answered no. But later, when asked if he had any difficulties with food or drink, he said this:

Swallowing... I don't know, maybe it's a feeling... Always I feel... always, when I swallow food, even water, when I want to drink water, I fear I will choke.

This participant did not report any incidents of choking, but he was afraid nonetheless. Another male with Parkinson's, Abdullah, also expressed fear of choking:

I have to chew slowly... and take breaks... I have to, so I don't choke... I once choked and I thought that was it... I did Shahada.⁷

This participant thought that this incident of choking was so serious it would end his life, and he performed an Islamic ritual of death. Abdullah had been seen by a SLT for both his communication and swallowing problems. Another statement came from Hadeel, carer of a woman with Parkinson's (Aisha, a 70-year-old female with Parkinson's for 10 years).

She once choked on a piece of sweet, the one they serve with tea, and she had violent coughing, and everyone started to hit her on the back and bring water and made such a fuss! She was so embarrassed, the poor thing, she start[ed] to refuse anything they serve when we go out.

These quotes demonstrate the fear of choking faced by people with Parkinson's and their carers. The first participant held this fear despite having no history of choking while the second had experienced choking and thought it would cause his death. The last quote shows the social aspect of a choking incident: how it prevented the person with Parkinson's in

⁷ *Shahada*: a statement of affirming the Islamic faith. People on their death beds or who think they are dying are expected to say it.

question from eating during social gatherings, therefore affecting her social life. This will be discussed further when addressing the psychosocial impact of these changes.

One of the recommendations that SLTs usually give to patients diagnosed with dysphagia is restriction from one or more types of consistencies. This is typically based on the instrumental swallowing test used to assess patients (as discussed in Chapter 2). In this case, the patient's food is modified to be safe for the patient. The people with Parkinson's and carers who discussed this type of eating change in their interviews did so in relation to the loss of the pleasure in eating for the people with Parkinson's. Nasir, who was 85 years old and had been diagnosed with Parkinson's for 13 years, said,

My daughter mashes the food for me... It becomes mashed... You know mashed food? ... Like the babies' food...It loses its flavour... but Alhamdulillah.

While, Abdulrahman, a 75-year-old person with Parkinson's said this:

I cough with liquids... [the SLTs] banned me from [drinking liquids] ... [but] not all of them... like tea... coffee... They banned me from them... I wish for a tea bialah⁸ but we have to listen to them (smiles).

Restrictions on food will be discussed again with regard to the situational experiences of eating and drinking changes and also in the discussion chapter as part of the impact on the carer's burden.

Another change that people with Parkinson's experienced was their difficulty in swallowing their pills. Although this has been addressed in the literature (Miller *et al.*, 2006), only one participant with Parkinson's and one carer who were not related mentioned it. First, Manal, a female carer of a male with Parkinson's (Abdulaziz, an 81-year-old who had had Parkinson's for 16 years) explained their experience with this problem:

His medication is also hard for him to swallow... He can take it with water but not all the time... There are times when he cough[s] and the pill [falls] out of his mouth... There are time[s] [when] he said he didn't swallow it, and I had to stick my finger inside his mouth and try to get it out (grimaces)... He has to take this medication... It's important... It makes the tremor much better.

⁸ *Bialah*: a small glass cup in which traditional tea is served.

This statement reveals the struggles that both the person with Parkinson's and the carer endure so the person with Parkinson's can take his medication. It should be noted that this patient takes his pills three times a day. The impact of this tiresome activity on people with Parkinson's and carers will be discussed later, along with the other themes of carer burden in relation to changes in eating and drinking.

The only person with Parkinson's who mentioned a difficulty with swallowing pills was a very pleasant, smiling man who had very obvious tooth decay. Khaled, a 56-year-old man with Parkinson's who had had a Parkinson's diagnosis for 7 years, mentioned his inability to swallow pills when asked about his health. His reply was this:

My teeth (smiling broadly)... See my teeth? ... They are in a very bad shape... My teeth are really worrying me.

When I asked him why, he said the following:

I have to break all my pills with my teeth... I break them and chew them... I can't swallow them... All these medications (points to a plastic bag hanging from his wheelchair) burned my teeth.

The medical record of this participant with Parkinson's had a very long list of medications that he had taken for a number of chronic diseases including Parkinson's. It was obvious from his tooth decay that this had been going on for a while, but when asked what had been done to resolve this problem, he said this:

Nothing... What can they do? ... Hmmm, tell me! ... I need this medication so I can move (stands up from the wheelchair)... See! I have to take it.

It is important to mention that this person with Parkinson's was never referred to the swallowing clinic. This will also be addressed later in the discussion chapter. After the interview, the neurologist in charge of this patient was notified, and referred him to the swallowing clinic.

4.3.2 Social impact of eating and drinking changes

In Chapter 2, the Saudis' meal customs and etiquette were reviewed. These include the importance of eating while sitting on the floor, of using only the right hand, and of not using utensils, except for spoons when eating soup. Food is served on one large, round plate, and each person must reach for it as they eat; only three fingers (not the whole hand) are used to

eat. One's legs must be bent under oneself, or else one must sit cross-legged. Older people are expected to start eating before others. Because families are large, meals often involve large numbers of people. Due to Saudi tribal customs, distant family members often visit (weekly or even more frequently), and sit and eat with the rest of the family.

With regard to processes unique to people with Parkinson's in this culture, subjects described how their muscle rigidity made it difficult for them to perform the movements needed to eat in an acceptable manner, such as cutting food and bringing food and drink to one's mouth without spillage. Traditions related to eating are challenging for people with Parkinson's regardless of their culture, but the cultural norms of this population include unique issues. For example, the participants explained how their motor symptoms restrict them from eating in the ways that are typical within their culture (such as sitting on the floor to eat in an acceptable manner). Their hand tremors made it challenging for them to eat with their hands and to drink coffee or tea while holding the small cups that are traditional in Saudi Arabia. The SLTs of some of the participants had restricted them from drinking liquids; this made it difficult for the people with Parkinson's to serve coffee to guests because they then had to explain to their guests that they could not drink with them. Some of the participants with Parkinson's reported that they isolated themselves during meals or other social gatherings for this reason.

At the beginning of each of the interviews, the focus was a discussion about eating and drinking changes that they had experienced. Some of the participants started the interview by discussing their motor symptoms. When asked specifically about the difficulties they faced when eating, many of the participants described how their motor symptoms had made them unable to sit on the floor like "normal people", and therefore they could not have "normal meals".

In Saudi Arabia, most people eat on the floor, but some people with Parkinson's expressed in their interviews that they could not sit on the floor comfortably. Culturally, it is not acceptable for a person to extend his or her legs when sitting on the floor. The quotes that follow discuss some of these issues.

Fayza: My legs are weak... Alhamdulillah, they still can support me when I walk, but not for long, and I can't sit for long; they get stiff and very hard to move.

Alhamdulillah, I can sit on the sofa but not on the floor.

INTERVIEWER: *And how has that affected you?*

Fayza: *I no longer eat with my family... They bring me my food to the majilis⁹ because it is the only room in the house that has a sofa, and they bring a small table to put the food on, but they eat in almakalat.¹⁰*

Fayza, a 68-year-old women who had been diagnosed with Parkinson's for over 8 years was fully aware of her Parkinson's, and, as the quote shows, linked her motor symptoms to her separation from her family during meals. Later in the interview, she stated,

Fayza: *I used to sit and eat with them, and then they would help me up when I started to feel the stiffness; but now I can't reach the floor, Subhanalah.¹¹ It is now very far... It is safer for me to sit on the chair.*

And when I asked her why they did not buy a table so they could all sit and eat, she said this:

Fayza: *No! It is not their fault... I am the one who has this condition; they can sit on the floor. No, no...*

It is obvious that eating on the floor is a strong part of Saudi eating customs; Fayza's family, therefore, did not consider changing their eating habits, and Fayza seemed to be in agreement that they should not.

Another participant's family did change the way they sat at meals and had bought a table for meal times, but the wife of a man with Parkinson's explained in the interview how this change had been difficult. Hailah, the only wife-carer in the study, explained the issues the family faced when eating with her husband (Ahmed, a 58-year-old with Parkinson's for 8 years).

Hailah: *I am used to it now... I don't like it, and my children don't like it. When my children bring food from the restaurant and Ahmed is asleep, we sit on the floor [laughing], but when we have our meals together, we eat at the table.*

INTERVIEWER: *So you eat at the table when he is with you?*

Hailah: *Yes. Sometimes my boys don't come to eat with us—they are out—and when they come back, I put their food on the floor... I know they want to sit there.*

⁹ *Majilis*: the area in a house for formal sitting.

¹⁰ *Almakalat*: the dining room.

¹¹ *Subhanalah*: an Islamic phrase meaning "Glory to God", usually used as a phrase of exclamation (Praising God).

This family had two meal settings: one for when the family member with Parkinson's ate with them and one for when he did not. This setup shows that the family was not comfortable eating at a table; they used opportunities when their father was not eating with them to eat in the way that was most comfortable to them. This also shows how the participant's condition placed an additional burden on the whole family, not only on the carer. This carer had explained earlier why sitting at the table was easier for her husband:

Hailah: *[If he sits] on the floor, he will get very tired—[it is difficult for him] even to get up from the floor. The chair is easier for him, sitting and standing is easier... On the floor, he likes to stretch his legs, [but] he can't stretch his legs and eat... Also, it is easier to eat [at the table]... because the food is nearer to him.*

The challenges that the people with Parkinson's face from their motor symptoms were difficult. The following interview shows how a person's condition affected his social life:

Mansoor: *Wallah, it has been a while since I went out.*

INTERVIEWER: *Why is that?*

Mansoor: *I can't relax while sitting.*

INTERVIEWER: *What do you mean?*

Mansoor: *I get tired from sitting. Now I'm tired from this chair (points at the wheelchair he is in).*

Sitting, in general, was very difficult for this man with Parkinson's, which was why he no longer left his home.

In another interview, a carer (Adel, the 38-year-old son of Ali) expressed the embarrassment his father faced because of his limited ability to sit on the floor. Because of cultural considerations, this man with Parkinson's would rather get up and not eat than change his sitting position:

Adel: *If someone is with us on the sufra,¹² he will not stretch his legs. He will be in pain... I will tell him, "Father, stretch your legs", but he will not... and then he asks us to help him get up, and [he] leaves.*

¹² *Sufra*: a mat or floor cover on which people sit to eat.

A cultural custom surrounding food in Saudi Arabia that is a challenge that people with Parkinson's face is eating with their hands. Saudi customs dictate that a person must eat using one hand only (the left hand should never touch one's food); the person must use this hand to both cut food (such as meat) and to eat. The custom also requires that a person's food must be contained in his or her palm; it must not touch the wrist. These eating customs are challenging for someone who has tremors.

Fatmah: Look, look [she raises her right hand, showing me her tremor] ... This is the problem... Can you eat when your hand is doing this?

A male with Parkinson's (Ahmed) whose problems with hand control had directly affected his mealtimes illustrated these effects:

The spoon is heavy, and someone has to cut the food for me....When I get upset while I'm eating, my hand gets tired, and then my eating will be affected; I can't hold the food because of the tremor.

Although the previous quote shows that changes in hand control directly affected this person's ability to eat, it also shows how he attributed the change in his hand control to the fact that he was upset rather than to the disease itself. This will be addressed in the discussion chapter, which reflects on the ways in which the availability of Parkinson's services in Saudi Arabia affect patients' access to care and, subsequently, their ability to understand their condition.

One female carer expressed how hand tremors had made her father self-conscious of his eating difficulties. She touched on the culturally specific father-daughter relationship:

Manal: I think it is because of the way he eats [that] he doesn't like to eat with us....he eats in a childish way... I mean... like when my nephews started to use the spoon... You know... the food drops from the spoon before it reaches his mouth, and food is left on his beard sometimes, and it is very uncomfortable....I mean, he has food left on his face... on his beard... and, ahhh, you can't tell him to wipe it because, you know... he is your father... He is not a child... so we leave him like this... with food on his face... It is very uncomfortable.

This carer compared her father to a child in the way in which he handled his spoon. However, though she was his carer, she felt unable to address this problem; she was willing to leave him with a "mess" on his face rather than confront him and ask him if she could wipe his face.

This carer was aware of her father's swallowing problems and had discussed them with his SLT, but she admitted that she could not be open with her father about his eating difficulties or talk openly with him (or with the rest of the family) about which foods he was restricted from eating. This could be related to an aspect of Saudi culture in some families in which females do not have a voice. In the discussion chapter, the issue of the carer's gender will be discussed.

The next quotes are from an interview with a daughter-carer (Amal, the 26-year-old daughter of Monera, a 61-year-old female with Parkinson's for 10 years); her words reveal the struggle that her mother and her family face at meals, during which her mother has challenges with her hand tremors:

Amal: As you know, this disease makes the person shake, and sometimes my mother's hands shake severely... When she eats, she makes a mess around her, and also on her face... I think... I think this disease makes the person have less sensitivity in the face.

When she has food on her face, she doesn't feel it... I have to tell her... Ahhh, I have to wipe it myself... and [when I do] this... she gets upset! And she doesn't eat anymore... She [has stopped] eating with us because she feels everybody is watching her.

This daughter described the way in which her mother had eaten since being diagnosed with Parkinson's. The quote above was part of her answer to the question of why her mother had isolated herself and stopped eating with the family. Amal had observed her mother's tremors during meals and had also observed the results of these tremors. She expressed very clearly that the tremors had affected her mother's desire to eat with them and that this was the main reason that her mother had isolated herself during family meals. In this part of the interview, Amal's tone of voice increased, and she appeared to be emotional while discussing this specific issue. She explained further:

Amal: She makes a mess... Her face has food on it... If she is eating with her hand, the food is all over her hand and on her clothes... Here and here (points at her sleeve and her chest)... Astaghforallah!¹³

¹³ *Astaghforallah*: an Islamic phrase used when a person is seeking forgiveness from Allah because he/she feels they did wrong.

When we finish eating, there is food on the floor surrounding her... You see in her place the food is everywhere and—(sighs) La elah ela Allah—and later, when we bring the vacuum, she gets really upset. She hates that.

Here, the carer described the mess her mother made while eating. She expressed her frustration by using the religious phrases *Astaghforallah* and *La elah ela Allah*, which people use when expressing exasperation or difficulty in articulating a problem. This section of the interview demonstrated the additional burden placed on the family, who had to vacuum their dining area after each meal; it also described the emotional reaction of this individual with Parkinson's. The next part of the interview clearly explored the emotional outcome from the eating challenges this mother faced. The daughter provided an insight into the dynamics of a Saudi family:

Amal: The problem is not me saying "swallow"! ... The problem is that she is making a mess when she eats, and she has food stuck to her mouth, and I have to wipe her mouth... I think, ... that she doesn't want anybody to see her eat like this... But I think that she started eating alone because of my father. She doesn't want her husband to see her eating this way.

INTERVIEWER: *But he is her husband... her life partner.*

Amal: And that's why he has to see her at her best!

INTERVIEWER: *What happens if he sees her at her worst? (Smiles)*

Amal: (Laughs) You want him to marry another woman?!

Interviewer: *(Laughs)*

Amal: No... Um, I don't know... No! No... I don't think my father will do it... maybe other men [would].

The patient's hand tremors resulted in difficulty eating, which resulted in making messes during meals. Due to the dynamics of the Saudi family and the societal rules that govern the wife and husband relationship within Saudi culture, this woman with Parkinson's decided to isolate herself whenever she ate. This was the way in which she decided to cope with her disease. This section of the interview might also shed light on why there are no husband carers in the sample of this study. Although a lot of research that comes from the US and Europe indicates the involvement of spouses in caring for people with Parkinson's

(McLaughlin *et al.*, 2011), this was not the case in this study. This will be discussed further in the discussion chapter.

The embarrassment that was expressed in the previous quote is not specific to females only. One man with Parkinson's clearly stated that he stopped socialising due to his eating difficulties.

INTERVIEWER: *What about in social gatherings?*

Abdulrahman: *I don't go.*

Interviewer: *Why?*

Abdulrahman: *Because I can't eat; my hand gets numb, so it becomes difficult to eat.*

This brief exchange shows a cause and effect relationship. It shows how essential meals and the act of eating are within Saudi social gatherings and how it was easier for this man to stop attending social gatherings entirely than to attend them but have to excuse himself before the meals are served or struggle while eating.

Of all the drinks that a person with Parkinson's might have, coffee appears to have been the most challenging for the interview subjects. They mentioned coffee more than any other liquid in the interviews. As I discussed in the Saudi customs section of chapter 2, drinking coffee—and the customs that surround how it is served and consumed—is an important aspect of Saudi culture. Drinking coffee is made more difficult for people with Parkinson's by the likelihood of aspiration.

Aspiration is commonly associated with Parkinson's (Suttrup and Warnecke, 2015). SLTs usually request a VFS or an FEES¹⁴ to assess swallowing. Based on the findings, they then give the patient instructions, which may involve restricting him or her from habits that could be causing their aspiration, typically the consumption of thin liquids. In such cases, SLTs ask the patient and carer to ensure that the patient does not drink any type of thin liquids, such as water, coffee, or tea. Also, SLTs usually prescribe a powder that, when mixed with thin liquids, thickens them to the degree that they become safe for the patient to drink. From the interviews, it appears that the restriction from drinking thin liquids was a very difficult instruction for people with Parkinson's to follow. The participants mentioned the challenge with coffee more than any other liquid, likely because it is such an integral part of socialising

¹⁴ FEES Fiberoptic Endoscopic Evaluation of Swallowing. A Procedure that uses a very small tube with a camera and light on the end that is connected to a computer and video monitor.

in Saudi culture. They most often reported their experience with hand tremors that cause them to spill their coffee. This problem is made worse by the fact that it is a Saudi custom to drink coffee from a very small cup (see Image 1).



Image 1: A typically miniscule Saudi coffee cup

The people with Parkinson's and their carers both talked about their experiences with Arabic coffee cups. Abdulaziz, a male with Parkinson's described his challenge thus:

Trying to hold the cup is not easy with this (points at tremors)... I can spill the coffee... My son make[s] sure that he pour[s] little coffee.

Another male with Parkinson's (Nasir) said this:

My boys put the cup on the table beside me... When we have guests... I wait until it is cold and try to lift it (smiles).

Later he said,

[Our guests] look at me when my son [places my cup on the table], but what can I do? ... I don't want to burn my hand (smiles).

Abdullah, a male with early-onset Parkinson's, explained how he now avoids his family's guests because he is expected to join them in drinking coffee.

I tell my brother to help me to my room... I don't want to sit in the majlis when [guests] come...

When the interviewer asked what happened to make him avoid his guests, he said,

I know I spill the coffee... so I don't let [my brothers] pour it for me... [Our guests] look at me... It is rude not to drink coffee with your guest...I don't like coffee anyway (smiles).

These quotes show that there is a challenge in drinking coffee that relates to the cup it is in and how and with whom it is consumed. In the case of coffee, Saudi custom governs how coffee should be poured, presented, and drunk. None of the participants mentioned drinking coffee with a different (larger) cup, although in the previous section, a carer explained how his father managed to drink soup by substituting the spoon with a large cup.

4.3.3 The emotional impact of eating and drinking changes

From the previous discussion and quotes, it is clear that people with Parkinson's and their carers and families are faced with challenges in dealing with the changes and the maintenance of normal family and social life. This struggle has resulted in a range of negative feelings on the parts of people with Parkinson's and their families, as discussed below.

One of the effects of the swallowing changes noted above was isolation, a term used to indicate the restriction of people with Parkinson's from social activities. Many participants had become confined within their homes or to socialising with specific groups of people. This change was connected to walking and mobility challenges but also to the eating changes they had experienced.

The following response from Hailah about her husband Ahmed, shows how eating changes caused him embarrassment, which resulted in isolation. Both of these feelings were caused by the changes to his eating. In a response to a question of whether the eating changes affected him, she answered,

Yes, ya omri! (Poor thing) it did! And that's what made him more unsocial and... more isolated... He doesn't want anybody to notice anything about him... I think that his problem increased because of his attitude towards his disease... Although, Alhamdulillah, everybody is telling us that the [type] of Parkinson's he has is... the simplest [form of Parkinson's] possible.

The carer elaborated by explaining that she thought this was caused by his attitude towards his Parkinson's. In her mind, his embarrassment is causing his isolation and he may have contributed to his own situation because of his attitude about his illness. This elaboration also foreshadowed issues that will be expanded on in the discussion chapter such as: Do people in

Saudi Arabia have enough information about Parkinson's to cope with the disease or to understand the changes to people's daily living habits that the disease causes?

In an interview with a female with Parkinson's (Fatmah), she discussed how she needed her maid to help her eat but that this was not socially acceptable in social situations. In the following exchange, this need for someone to help with eating had caused this woman to isolate herself and not to go to *azaym*.¹⁵

Fatmah: *I can't sit for long [because] my body hurts me... and I can't bring her (points at her maid) with me.*

INTERVIEWER: *Why? I know a lot of women who have their maids with them in azaym.*

Fatmah: *Yes, but they stay with the other maids... She must sit with me and help me eat... No, no.*

In the following conversation with carer Hadeel about her mother (Aisha), the carer complained how her mother had isolated herself to the degree that she no longer ate with her family or allowed anybody to eat with her—even her own carer/daughter.

INTERVIEWER: *You said you bring her food on a tray and come back later to get the tray... You don't eat with her?*

Hadeel: *No, I don't.*

INTERVIEWER: *Can I ask why?*

Hadeel: *(Speaking in raised voice) That's why she is in her room! ... She wants to be alone... She doesn't want anybody to see her eat! ... Allah knows best... But I think that she doesn't want anybody to see her while she is in this condition.*

Interviewer: *Aha.*

Hadeel: *...Especially when she eats! ... She doesn't like anybody to see her eating... But also, she doesn't want them to see her tremors, you know, the way her body shakes... Her hands, they shake, and a person can't help but look at her hands... She gets shy and embarrassed, and maybe this is what causes her to isolate herself.*

¹⁵ *Azaym*: a word used to describe all kinds of social gathering.

In the same interview, the carer pointed out when the isolation behaviour had started; it was caused by a combination of the severity of the disease and a decrease in the medication's effectiveness.

INTERVIEWER: Alright, and when the medication started to not improve the way she ate... what happened?

Hadeel: That's when the isolation happened! The medication used to make the tremors less [severe] ... and she used to feel better... as if she was normal... But now, the medication is not effective, and her hand shakes so much when she eats, and also she doesn't feel the food on her face... My mother always (she prolongs the word "always") has a tissue with her... all the time, and she always wipes her chin, even if there is no food on her chin, but she doesn't know that there is food on other parts of her face! (Talks rapidly)... Now she doesn't want to eat.

The frustration that this carer felt is obvious in her response and also in the other cues she gave, she used a raised voice when she discussed her mother isolation and she was talking rapidly and prolonging specific words when she was explaining all the struggles that made her mother don't want to eat with the rest of her family. It was obvious just from her behaviours in this part of the interview that this isolation issue is very hard on her. She, as well as several other carers, expressed frustration toward the person with Parkinson's choosing to isolate themselves, showing that some carers may think it is unnecessary.

To conclude, eating and drinking customs in Saudi Arabia are linked to age and stage of life. Older people are expected to sit, eat, and act in a certain way. Parkinson's—and, in particular, the changes in eating and drinking that the disease causes—makes it difficult for people with Parkinson's to behave during meals as they are expected to. This causes awkwardness, which results in isolation, typically initiated by the person with Parkinson's.

Both carers and their family members with Parkinson's reported that the person with Parkinson's felt embarrassed during social events or family meals. Because Parkinson's usually affects older people, and the older generation in Saudi Arabia are unaccustomed to going to restaurants, which are new to the country, the feelings of embarrassment that were expressed in the interviews usually affected people with Parkinson's and their families in their homes or when visiting extended family. Abdulrahman, a 78-year-old man with Parkinson's, talked about eating with his family and how his Parkinson's prevented him from enjoying his meals:

It is humiliating to eat... this way... You don't enjoy eating... you know someone is looking at you.

In another interview, Abdullah, a 74-year-old man with Parkinson's said,

My sons are used to... the way I eat, but sometimes, we have guests or... sometimes, my sons bring their families with them... I don't like to eat in front of them [because] it is uncomfortable... I tell them I have a headache and need to sleep... They now know that, and they don't bring their families as they use to... but they have to eat with their children... (sighs) We now eat together once a week... or sometimes, one of them comes one day and another comes another day... They try not to leave me for long... May Allah bless them.

This man with Parkinson's was comfortable with his immediate family, but he got embarrassed when his extended family or guests came to eat with them. He would avoid eating with them by pretending to be asleep. Because his embarrassment was obvious to his guests and extended family, they began to visit him less often. This part of the conversation demonstrates how changes in his eating abilities had caused him to become embarrassed, which, in turn, caused him to isolate himself from his guests during meals. This resulted in his extended family and guests not visiting as often, thus causing a change in the family's social life. In the same interview, Abdullah discussed the changes that had happened during meals:

Abdullah: ...I can't reach the tibs¹⁶...and they have to bring me a plate... just for myself.

INTERVIEWER: *How do you feel about that?*

Abdullah: ...Of course, it is upsetting... and it is uncomfortable for me and my guests... but what can we do? ... Alhamdulillah.

An inability to eat in the traditional Saudi way (from the same plate) caused embarrassment to Abdullah and his guests. Most Saudis eat sitting on the floor and from the same plate, which means that one must be flexible enough to reach the central plate, and steady hands are necessary for carrying the food to one's mouth. For a person with Parkinson's who suffers from rigidity and tremors, this method of eating can be quite difficult. As demonstrated in this

¹⁶ *Tibsi*: a large, central plate that everyone eats directly from.

part of the conversation, Abdullah had to eat from a different plate than that shared by the others.

In the interview below, Fatmah discusses her maid's role in her care and why she did not go to social gatherings.

Who wants [to have to be fed] like a baby? (Touches her face) ...Allah will help me... a person [who has] reached this age ... and, Alhamdulillah, raised good children... now [I] want to die in dignity.

The maid was directly involved in feeding this woman with Parkinson's; the woman then refused to attend social gatherings because she did not want other people to see her being fed by her maid. Her embarrassment stemmed from needing to be fed; the presence of a maid in any other situation would not be a source of embarrassment. From this part of the conversation, it appears that having to depend on someone to feed her was distressful to Fatmah and that she saw this situation as a loss of her dignity. Saad explained further,

I can't sit for long... and sometimes the person... sitting next to me has to stop eating so that he can help me get up... My sons are sitting far [away] ...not with me... The person sitting beside me... has to stop eating and... help me get up... and sometimes, they have to take me to the washing basin... because, when I get up, I still need help walking... They don't go back to eating... I try to let them go back to the sufra, but they refuse.

Saad gives a clear description on how people in Saudi Arabia eat in large gatherings. Usually, the older generation eats together; this man, therefore, missed his sons' presence beside him to help him. Because he was uncomfortable and still needed to get up, the person beside him (who was of the same age group) had to get up to help him stand and support him while he walked. It is this unusual early exit of the meal that Saad has to do that disturbed the meal of the other guests or host. In addition to embarrassment, this also demonstrates how it was distressing to this man to have the people around him disturbed in their eating as a result of having to help him.

Hailah the only wife of a man with Parkinson's discussed the theme of embarrassment from a different angle,

I don't want anybody to know the... what do you call it, the... the suffering. I don't mind anyone knowing he has Parkinson's... This is not a problem, but why do people

need to know that he needs help dressing or eating? ... This is none of their business... We will be gum in people's mouths.

This statement, "We will be gum in people's mouths" refers to a common Saudi saying that means that "We will be the topic of gossip". Embarrassment not only afflicts the person with Parkinson's but also his family. In the statement above, the wife is discussing the domestic help that they had at home and how much the maid knew about Parkinson's. The wife was comfortable enough to let the maid know about her husband's medical condition. In this particular quote, the wife is explaining what about her husband's condition was embarrassing to her. She did not mind that people knew about the disease itself, but she did not want them to know about the changes that came with it, including the difficulty in eating. In her mind, Parkinson's-related changes were potentially the cause of gossip. Despite acceptance of Parkinson's itself (as a condition) in Saudi Arabia as it is considered *ibtala* (see discussion chapter), people still talk and gossip about the details of the disease, the symptoms, and changes that are secondary to Parkinson's. Families of people with Parkinson's report being uncomfortable discussing it.

Below is a statement from Yousef, a male carer who talked about the changes in his family's life because of the changes in his father due to his Parkinson's:

Wallah... there are differences... I would be lying if I said there are no changes... We use[d] to eat [at] the farm more than [we do] now... Our uncles and cousins used to come more and have dinner with us, and we did the same... Ahhhh, my father, when we were on the sufra, he would talk and joke and yabashir¹⁷ (make sure everybody is eating/served food) ...Now, after this Parkinson's, he is not social... You know, he is now more concerned with his medications... and we are worried about his health... The family doesn't get together as before... but Alhamdulillah.

In this part of the interview, it is obvious that an important part of Saudi culture is the existence of extended families, who frequently meet for social occasions. The son misses the social aspect of gathering with his extended family and regrets that his father can no longer play the same role during these activities that he used to.

Another feeling that participants reported was the feeling of not being useful or participatory in regular family routines. This theme manifested only in the interviews with the participants with Parkinson's; the carers did not mention anything related to this theme, either regarding

¹⁷ *Yabashir*: the host make sure everybody is eating/served food.

themselves or the person they cared for. In some of the interviews, people with Parkinson's mentioned that they were happy and content that they had reached an old age; they were not overly concerned with what would happen next. As two males with Parkinson's told me,

Abdulrahman: I have seen things that no one saw in this life. I am happy that I reached this age, and I am now ready for whatever Allah has [in store] for me.

Nasir: The one [referring to himself] is not like before, [when] you work and you bring food to the children... Now, you sit from sunrise to sunset doing nothing... pray, sit, pray, sleep, pray, eat, that's your life. But we say "Alhamdulillah".

These two quotes, along with the tone of voice in which they were spoken, show a duality in perspective. On one hand, they suggest a sense of satisfied completion of the productive stage in life. Both speakers were males in their sixties who had had Parkinson's for over 10 years; both had worked but were now retired. Their words suggest acceptance of Parkinson's and old age as well as whatever is ahead of them in life. On the other hand, they show a dissatisfaction or dismay about not being part of the productive part of the family any longer. The feeling of uselessness comes because there is a shift in the role of the person with Parkinson's from being the decision maker and leader of the family to a point in which the person feels that he or she is a burden. Parkinson's, and the changes that happen to people with Parkinson's as a result of it make this shift both drastic and prominent. Monera, a 61-year-old female with Parkinson's for 10 years was discussing the chores that her daughters are doing now for her:

I don't know what they are doing in the kitchen... now I only see the food [when] they bring it to me... I was the one cooking and they help... they use to only help when I ask... now I just sit and watch them do everything.

This statement appears in the middle of discussing the duties of her daughters, linking her uselessness to additional burden on other members of the family. This is a woman who until her 50s was in full responsibility of her house duties. Now, with her Parkinson's, she has noticed the shift in her role in the family.

People with Parkinson's face many changes throughout the course of their disease. Eating and drinking are two of the most crucial functions that are affected by Parkinson's. Changes in eating and drinking that are experienced by people with Parkinson's like prolonged eating and drinking time, fear of choking, and restriction of types of consistencies are universal and can be experienced by any person with Parkinson's in any country. These eating and drinking

changes have a culturally specific tone when they combine with other challenges that are specific to the Saudi culture, like the difficulties of eating on the floor or eating with the hand. These characteristics of the culture influence people with Parkinson's in that they are not able to participate in the customs of drinking Arabic coffee with guests or eating with the family without disturbing them. These changes make coping difficult and result in an impact on the person's social and psychological wellbeing. As one of the people with Parkinson's said in a short defining statement that summarised all of these changes: "The whole meal is awkward". He said this in frustration while we were going into detail about the changes he faced during meals. It is apparent that many of the participants with Parkinson's felt "awkward" when trying to eat a meal within a society that has certain rules that govern how a person should eat—especially when that society also has limited knowledge of Parkinson's and, thus, its people may be unsympathetic to differences from their social norms.

4.4 Theme two: We all have Parkinson's

4.4.1 Carers' experiences

The previous section reported how people with Parkinson's experienced and perceived their Parkinson's affected their eating and drinking. This section presents the findings with respect to the relationship between the carer and the person with Parkinson's as well as how the changes to eating and drinking habits that people with Parkinson's experience affect the carer and relationships with immediate and extended family. Specifically, this theme shows how meals play a strong role in the relationships and structure of the Saudi family. They show that the changes people with Parkinson's undergo in their ability to eat and drink normally have drastic effects on their roles and participation in these meals and, subsequently, in the social events within which these meals occur. The interviews also demonstrate the stress that carers endure when dealing with these changes within social situations.

Studies on the impact of disease on families have typically investigated only the nuclear family, which is how Western countries define the family (McLaughlin *et al.*, 2011). In Saudi Arabia, however, the influence and history of tribes yield a different meaning of family: a family in Saudi Arabia also includes the adult children and their families. In some Saudi Arabian cultures, a man and his wife may have their sons living with them even after the sons marry and have children. The distant family members, including uncles, aunts, and cousins, are also present in the nuclear family, and their involvement differs from that seen in the U.S. or most of Europe.

All of the participants in this study expressed some form of discomfort or difficulty when talking about eating and drinking. In their interviews, some of the people with Parkinson's provided examples of meals they had had with their children, while others spoke about issues they had suffered while eating with relatives. The carers provided more detail on the difficulties both they and the people with Parkinson's experienced during meals and described how mealtimes had changed from taken-for-granted, normal, everyday activities to stressful events.

People who have neurological conditions like Parkinson's and are living in the community receive the majority of their care from informal carers (World Health, 2006). This is particularly true within Saudi culture, since the country has very limited options for residential and nursing home care or social services. One might say that there is a cultural expectation surrounding caring for relatives. For example, there is certainly an Islamic expectation. Although informal carers can be wives, husbands, daughters, sons or other relatives or friends (Glenn, 2007), in this study, it is significant to note that daughters represented the largest group of carers and that there were no husband carers. In the interviews, the daughter carers spoke longer and provided more details than any other group of participants. Some might argue that Saudi culture is hard on females and that daughters are often forced to care for their parents. However, while this may be true in some cases, the finding of this study show that regardless of the family's educational and socioeconomic background, daughters tended to want to take care of their parents. When the interviewer asked one female with Parkinson's about the impact of eating and drinking changes on her, her first response was,

Aisha: Alhamdulillah, I am very lucky. My daughter... my children are good Muslims... they take care of me and are always around me...

In Saudi culture, children are usually the carers for their parents. The above quote shows that the first thought that came to this person's mind when asked about the impact to her of the eating and drinking changes was that she was a mother of children who had strong Islamic values; therefore, she was fortunate. Taking care of parents is something that all families expect of their children; thus, when a parent becomes ill, it is expected that one of the children will be the one to take care of him or her. Usually, the task falls to an unmarried daughter.

The burden of care was expressed when carers described how they deal with the eating and drinking changes of their family member with Parkinson's. When discussing how these changes affect them, they started with recognizing themselves as the ones providing care,

based on their gender. This carer, May, daughter of Mansoor, who had had Parkinson's for 7 years stated,

I am the girl [the daughter]! I am the one that is caring for my father.

She spoke it as a statement, as if she were saying, "who else [would care for him]!" Another daughter-carer (Dalal, daughter of Abdullah) made the following statement:

While we are eating? I am the one that helps him... sometimes my sister helps me, but usually I am the one that deals with his food.

Later, when asked about her mother's contribution to care for her father, she said,

It is hard on my mother and, I think, hard on my step-mother. My mother is an old woman, and my step-mother is busy with her children.

This quote shows that, in a culture that allows polygamy, having more wives does not necessarily mean that wives will be the carers. In this case, it appears that the daughter was the carer, regardless of how many wives the patient had. The daughter explained that if anyone were to help her, it would be her sister, not her mother, and she suggested that her mother's age and her step-mother's busyness were the reasons she was the main carer.

A similar pattern emerged in an interview with a male carer. Raid, who self-identified as the main carer, was interviewed for his father (Saad). During the interview, it became clear that the daughter did most of the direct caregiving in the home.

We all help him. If he wants to walk, we support him... you will find one of us with him. We all help, but my sister is the best one in caring for him when he wants to eat. She alone knows him. She knows what he can eat and can't eat. She knows how to help him and what she needs to cut for him... she is his right hand (smiling). That's why, as I told you, he can't go to azyam: he can't take her with him (smiling).

It is not clear from this quote why the daughter is the sole carer in eating and drinking. The explanations that "she is the best one" and "she knows him" are not sufficient. What is clear from this quote is that this son considers all of his family to be carers but his sister to be the one most suited to the eating process. The interviewee referred to his sister as "the right hand". This might symbolically mean that his father cannot do anything without her, or it could mean that his father cannot eat without help from the sister; thus, because Muslims must eat with their right hands, she is the *right hand*. This carer also touched on an important

subject within the Saudi culture, which is gender segregation. The carer during meals is a female. If the person with Parkinson's is male and females cannot attend males' social gatherings (*azaym*), the person with Parkinson's cannot attend. The effect of gender segregation on how people with Parkinson's and their carers cope with eating and drinking changes is addressed in the discussion chapter.

The intensity of the burden of care was discussed throughout the interviews. When asked what she had to do to help her father during meals, Dalal, the female carer of Abdullah, said,

It is all exhausting. I feed him and I have to wipe for him, yes, but this is not all. From the morning until night time we are with him, feeding, washing, dressing and this and that. It is very draining.

Her description shows that feeding is just one part of the caring process; there are many other changes to which the carer must adapt and with which she must deal. Feeding adds to the carer's overall burden.

The carer's relationship with the rest of the family is also impacted, as shown in this quote from the same daughter-carer:

Of course they [brothers] don't help! They don't know how and they don't want to know how to help him [father]. To be honest, they now don't eat with us like before.

This quote was a response to the researcher's question about whether the daughter had help from her brothers. Her answer shows that the burden of feeding their father fell solely on her shoulders and that she feels that the others ran away from it. This same carer also discussed her duties and how her brothers' food preferences added to her workload:

Cooking is a problem. I cook for him food that has no salt in it, and they [brothers] want only salty food, and also I can't cook for him lamb Kabsa¹⁸ because of his teeth, and they want only lamb Kabsa (smiling).

This carer expressed some frustration at the added burden of preparing multiple meals for the men in her family but also smiled while describing her role. This duality suggests that she is burdened while at the same time showing some acceptance. This was expressed in other ways in interviews with another carer and person with Parkinson's. The following quote shows how

¹⁸ *Kabsa*: a traditional Saudi dish, which is rice cooked with meat or chicken.

this extra cooking duty can be straining on the family. Haya, who is a female with Parkinson's for 9 years, discussed her daughter Sameera's load of duties in the family.

The girls fight in the kitchen... everyday... fighting... I know it's too much on them... cooking for me and for the family... and Sameera is always busy and they [sisters] don't help her... (Long pause) I can't complain to anyone except Allah...

In the above situation, the added duty of cooking caused family friction and fights among the sisters. The burden of cooking separately for the mother was added to the duties of cooking for the family. It is important to note that the carer in question never mentioned the fights with her sisters during her interview, again suggesting acceptance of her role as primary carer, but she did mention that the burden of caring for her mother was affecting her life:

Sameera: I would like to spend more time on the internet.... but I can't. I am always with my mother.... and when she sleeps, I need to do other things for the house.

Later, she said:

Cooking takes a long time for me... because I have to cook for my family and I have to make special food for my mother... she can't eat meat or chicken... I make her soup... jaresh¹⁹... you know, soft food... I also have to feed her, and sometimes, because of the medication... I have to feed her before I finish the others' dinner.... it is messy... sometimes I am late for their [the family's] dinner, and my father gets angry.

These statements illustrate the challenges this daughter faced as a carer and suggest that other family members may have limited understanding of the extent and impact of her caregiving duties. It shows that she and her sisters fight, her personal time is limited, and her father is angry that these extra duties make her late for family dinner. It seems that the time it takes to complete her tasks is interfering with her everyday life.

Studies of the social lives of carers have shown that caregiving duties can affect carers' social lives (Schrag et al., 2006). The role of a carer is very demanding and can place a huge strain on the carer's social life and work, leading to isolation (Glenn, 2007). The findings of this study demonstrate this strain and its unique influence in the lives of Saudi carers. In response to a question about visiting her relatives, one female carer replied as follows:

¹⁹ *Jaresh*: Saudi porridge.

Hadeel: *Oh no (laughing), that is old times... now, if our relatives don't come and visit us, we don't see anyone for months.*

Here, through her use of the phrase “old times”, the carer expresses the difference between her social life before and after Parkinson's. It is apparent that the disease caused a significant change in this carer's social life, which is common for caregivers, but has different implications in the Saudi context. The practice of visiting relatives and hosting them is central to the social lives of families in this culture. Females, especially, are limited to these visits as their primary social lives outside of the people in their household. Caring for a parent with Parkinson's has dramatic changes on their social worlds. Another female carer, the 26-year-old daughter of a female with Parkinson's, gave a more detailed description of the changes to her social life:

Amal: *I miss the people of Dammam [a city on the east coast of Saudi Arabia, where this family was originally from]... they are our family... we have a group in WhatsApp [a popular application that is widely used in Saudi Arabia for texting] for all the [female] cousins, and we talk in it... they are always planning outings and parties.*

This female carer discussed how the family used to travel frequently to their hometown of Dammam, which is three hours by car from Riyadh, and how she enjoyed socialising with their extended family (cousins). However, their visits had become less frequent since she had become her mother's carer. The daughter then discussed why they stopped going to Dammam in more detail:

The car trip is not our biggest concern... the problem is that she will stay in the apartment (some Saudi people rent furnished apartments when they visit relatives), and then one of us [sisters] will have to stay with her... she doesn't like big gatherings... I am usually the one that stays with her...

Later, she said:

It is all hard on her, but it is mostly sitting, and having one of us [family] help her with the food... she doesn't like that... You know our people [Saudi]... they stare.

These quotes show the challenges to visiting others, including the mother's concern over people staring at her when she eats, her isolation due to her embarrassment during meals with relatives, and the resulting impact on her daughter's social life.

Another female carer explained how she felt as a result of the changes that had happened to the family routine due to her father's eating and drinking changes:

Manal: We changed our family time... Before my father's Parkinson's, my brothers and sisters would come to our house after isha [evening prayer] ... we drank coffee and tea and ate sweets, and we had dinner together... But we found this to be difficult for my father... he can't sit for long, and he can't eat with us, so my brother decided to change the time to come after aser [midday prayer] ... They already ate in their homes, and we sat together and talked, but they had to leave by magrib [sunset].

INTERVIEWER: How do you feel about this change?

Manal: I don't like it... I don't think any of them like it... They just come for two hours and leave... I don't like it... I spend the rest of the day alone with my parents watching TV... My sisters used to stay with us sometimes up to 3 a.m., but now they go to their husbands' families' homes.

INTERVIEWER: Aha... since no one likes the new situation, why not go back to the way it used to be before... like most families, after isha prayer?

Manal: I don't know. We are used to it now... And it is more comfortable for my father... As long as they visit and he sees his grandchildren, he is happy... they visit a lot, but they don't stay as long as they used to.

This narrative shows how changes in this family's weekly routine started when the father was unable to enjoy eating and drinking with his family. This change led to changes in the family weekly reunion time, which led to changes in the duration of the visits. It also shows how the father's happiness takes precedence over the daughter getting to socialise with her family.

The two above accounts illustrate how the daughters of people with Parkinson's are the ones who are most affected by the changes to the eating and drinking abilities of people with Parkinson's. For example, in the second interview, the unmarried daughter was the one whose social life changed. It is also relevant to observe that eating and drinking changes do not always have a direct impact on the carer's social life. However, changes in eating and drinking can cause other changes that impact the carer. These observations give insight into the complexity of the role of carers within the family in Saudi Arabia, which goes beyond the complexity of traditional carer roles.

While the duties of caring for a parent with Parkinson's tend to fall on the unmarried daughter, the interview with one daughter revealed that daughters sometimes volunteer to be the carers. This 39-year-old daughter, who used to work in a bank, decided to resign to help with the care of her father. She started working from home in order to keep a careful watch over him and was the only carer whose interview was conducted outside of the hospital.

During her interview, she said,

Asma: It is an honour to assist him... I don't see it as a burden at all! I am fortunate that I can afford to quit my job and take care of him... we are managing this disease well.

Later in the interview, she showed another aspect of caregiving that she experiences - a perspective expressed by many carers in the study. In addition to caregiving affecting their social lives, carers expressed sadness about seeing their parents struggle with daily activities because of Parkinson's:

Asma: I feel sad when I see him like this... We would be sitting together and you see your father, a great man that was feared by so many, and you see him now being fed by this Filipino! I can't describe to you my feelings!

This daughter expressed feelings of honour and sadness at being fortunate to be able to afford to care for her father but sad to see her father deteriorating. Similarly, in response to a question about how he felt about his father's eating and drinking changes, one son-carer answered,

Adel: My problem is that he feels that he eats in a strange way and that all the people are watching him.

From his use of the phrase "my problem" and his tone of voice, it appears that this son has strong feelings about how his father feels about his eating changes. The above quotes show that the impact on the carer goes beyond the burden of care and the carer's social life. The carers are emotionally involved with their loved ones' Parkinson's, and it has a strong impact on them.

One daughter-carer described the duality of sadness from seeing her mother having eating problems while not getting upset because of her belief that this process of a plan of the higher power - Allah.

Sameera: *My heart hurts when I see her like this... when she stops eating and I know she still wants to eat, but she gave up.*

No, of course, I don't get upset. This is Ibtala from Allah for both her and me. Alhamdulillah, we are people that can endure Ibtala, and we are confident that Allah is merciful and will not leave us.

Ibtala, an Islamic concept that revolves around God's testing of Muslims with diseases and medical conditions, will be discussed in more detail in section 5.5.3. However, in this quote, *Ibtala* was used by the carer to describe the meaning she and her family attribute to the experiences they are having with Parkinson's.

Another aspect of the caregiving experience that carers shared was how the eating changes affect all the aspects of the meal for the carer. In other words, the carer is affected not only by the tasks of cooking and preparing multiple meals along with feeding and cleaning, but also by the other aspects of meal time:

Manal: *I will be talking and, you know, I am telling a story, and then he pulls my dress... to let me know that I need to help him... and I start helping him with his eating, and then I forget what I was talking about (laughing).*

This daughter illustrates how her father's eating changes affect another aspect of the meal. When she is having a meal with her family and is engaged in conversation, she has an additional task—feeding her father—which prevents her from continuing stories or being a part of the conversation. One daughter-carer of a female with Parkinson's revealed another aspect of a disturbed mealtime:

Hadeel: *Actually, I stopped eating with her [mother]. I eat at another time... I am [so] busy with her and her food that I don't enjoy my meal... I am so busy with her that my food gets cold and I still didn't eat anything, so now I keep my food in the oven, and when we [the family] finish, I go and eat in the kitchen.*

This quote shows how the eating changes of the person with Parkinson's had a great impact on the carer. The degree of dependence on the carer for feeding prevented the carer from enjoying her meal, so she chose to eat alone after everyone else finished.

Carers are also affected by how much they need to do for the person with Parkinson's, which changes over time. Parkinson's is a progressive condition, which means that, with time, its severity increases and the person with Parkinson's loses more of his or her ability to perform

daily functions. In the following quotes from two different interviews, a son and a daughter explain how the burden on the carer became worse once their parent's eating and drinking abilities deteriorated:

Adil: It started as a simple problem. It was tremors, as they [doctors] called them, and later, he had other problems, like walking and sleeping and all that, and we were with him and, of course, now things changed, and someone has to be with him all the time... and like we were talking, now someone has to feed him. We can't let him eat by himself... Allah may help us, my sister, it is getting worse and worse, and we don't know what to do, and we don't know what will happen and what he will be like, but we just say Allah will help us.

This male carer notes the progress of the disease; this quote illustrates how changes in eating and drinking are part of the increasing severity of the disease, such that the person with Parkinson's ultimately is no longer able to feed him/herself. These observations were echoed by another carer - the daughter of a female with Parkinson's:

Sameera: It is getting worse and worse. She used to be able to eat, even with the tremors of her hand, but now, even with the medication, she still can't feed herself, and her coughing is getting also worse. She can't have a single meal without coughing now... I am worried... I am worried for her, but for me also... I sometimes think about the future and what will happen to us. It makes me think how my life will be... I get these thoughts all the time, but especially when I am caring for... when I am bathing her or feeding her.

In these quotes, this daughter-carer revealed her anxiety and worries for the future. She also expressed the strain carers experience due to their duties caring for parents with Parkinson's. This person's swallowing and eating was getting worse as the disease progressed, and the deterioration gave the daughter additional worries, preoccupying her thoughts about her own future.

4.4.2 The family's experience

The family of a person with Parkinson's is also impacted by his or her eating and drinking changes. The literature on Parkinson's and its impact has focused mostly on the person with the disease and the carer; in contrast, the families of people with Parkinson's have received little attention. The interviews in this study have pointed to the family's involvement in many

aspects of the disease, but they have particularly emphasized how the family is affected by the disease. One of the daughters gave a very powerful statement:

Asma: This Parkinson's is the disease of the family and not just him. We all have Parkinson's.

This 34-year-old daughter of a male with Parkinson's was answering a question about the impact of Parkinson's on her father. In her reply, she identified the whole family as being impacted. This statement gives insight into what might be happening within this family.

Another daughter of a female with Parkinson's answered a question about why the family did not go out the way they used to as follows:

Hadeel: If she just could eat in a normal way, things would be better. At least we [the family] could go out and visit.

This daughter's statement reflects how she felt about her mother's declining eating abilities and the effects of the decline on the social lives of the whole family.

4.4.3 Relatives (distant family)

Saudi families are part of a tribe. Therefore, a family does not exist without close ties to the rest of the tribe including cousins, uncles, aunts, second cousins, and so on. These relatives are part of the family's weekly (and sometimes daily) routine. Maintaining strong ties with family members is part of Saudi culture, but it is also a very strong general Islamic concept called *Silat-ur-Rahim*, which is discussed below.

A crucial Islamic tenet that is prominent within Saudi culture is *Silat-ur-Rahim*, which refers to maintaining relationships with relatives. This concept means that people must work to maintain their relationships with their relatives by visiting them and asking them to visit their homes in return. The word *rahim* means womb, and it is used in this context to refer to those who come from the same womb (family). *Silat-ur-Rahim* is mentioned in the Quran and *hadith* numerous times, either in contexts emphasizing the importance of maintaining *Silat-ur-Rahim* and the rewards a person gains (both in this lifetime and after resurrection) for doing so or in reference to the punishment people will receive if they sever their family relationships and do not work to maintain them. *Silat-ur-Rahim* is mentioned in the Quran fifteen times. Here is one example:

Allah commands doing justice, doing good to others, and giving to near relatives, and He forbids indecency, wickedness, and rebellion: He admonishes you so that you may take heed (16:90).

As mentioned in Chapter 2 in the discussion of Saudi culture and the influence of Bedouin communities, showing generosity by offering food and drink to visitors is a vital part of any visit. With time, this custom became the habit of general Saudi culture. It is now expected that, when visiting another person's house, one will partake in a meal. Usually, this is a family-style meal, and if the group is large, it will be a very elaborate one.

As mentioned earlier, in their interviews, people with Parkinson's and their carers expressed the challenges that social norms placed on the people with Parkinson's; Parkinson's made their visits to relatives (and visits from others) awkward, both for them and for their visitors. The result was isolation for the people with Parkinson's. The awkwardness also affected the very strong concept of *Silat-ur-Rahim*. In one interview, a carer explicitly mentioned how he had found it difficult to maintain *Silat-ur-Rahim* following the onset of his father's Parkinson's.

ABDULLAH: *They [referring to his relatives] don't want to visit anymore because they know how hard it is on him.*

INTERVIEWER: *So you don't see them anymore?*

ABDULLAH: *No, no, they visit... of course, they have to visit, but they now come for very short visits... you know, they come and say 'Alsalamo Alaykoom'²⁰ and leave...*

INTERVIEWER: *Aha.*

ABDULLAH: *They want to be sure we don't serve them anything.*

INTERVIEWER: *Can you explain more?*

Raid: When they come to our house, they are always in a rush; they always say they have to go and [that they] can't stay... we hardly have time to pour them coffee, and then they drink one cup and get up [to go]. They are uncomfortable; I think they are worried [that] they will have to sit and eat with my father and have to witness his problems—you know, see him struggle.

²⁰ Alsalamo Alaykoom: A phrase used when one enters or leave a group of people

INTERVIEWER: *Struggle how?*

Raid: *Struggle... struggle with trying to sit and eat with them, and all the things I told you about. It is hard for them to see their uncle like that.*

Interviewer: *[Nods]*

Raid: *Allah help us, but it makes it hard to keep relationships with our relatives. My father is the eldest of his brothers, and so all the cousins have to visit him, but they are having a hard time doing that; and it is also embarrassing for us now to receive all these people.*

INTERVIEWER: *Tell me why it is hard?*

Raid: *Hard [because] not everyone knows what Parkinson's is; if some older people come, they expect to sit and eat with us, and they stare at my father. And the cousins, like I told you, no, try to make their visits very short just to spare him the embarrassment. It is hard either way. It is not like before.*

This extract from an interview with a forty-year-old male carer from a typical Bedouin tribe demonstrates the struggle that the person with Parkinson's, his family, and his relatives faced as a result of the changes and the effects these changes had on his ability to eat normally. These changes had actually affected the way in which the family maintained its relationships. Because maintaining relationships is an important aspect of Islamic families, to not do so is an extreme misfortune. In the same interview, the carer described his feelings about this:

Raid: *His condition doesn't allow us to host our guests in the way we should—you know, the right way to host someone... and we don't feel comfortable when we visit our relatives because, when they serve us feasts, we can't do the same. They can do that because their lives have not changed. It is not fair. There is no balance. I don't want to go to someone's house and eat their food if they don't eat my food [in return]. Truly, it is humiliating. I [would] prefer not to go, actually, but I can't because it is haram [forbidden] to cut Silat-ur-Rahim.*

In another interview, a female with Parkinson's spoke clearly about how it was difficult for her to attend social gatherings and how awkward it was for her to sit and eat with others; she also stated that she had noticed their stares. Later in the interview, she talked about *Silat-ur-Rahim*, and how the new generation was no longer maintaining the custom as they should:

Fayza: *They don't care anymore.*

INTERVIEWER: *Who doesn't care anymore?*

Fayza: *The young people—they don't care about us anymore; before, they would come and visit and sit with their uncles and aunts and the elderly, but now I barely see them—once every month or every two months.*

This quote is an example of how *Silat-ur-Rahim* is dear to the older people in Saudi Arabia. They expect everyone in the family (including distant family) to fulfil this concept, and, therefore, expect people to visit them. This desire conflicts with their own feelings about their disease: that is, the urge to be isolated and not to socialise with others. Part of Saudi social norm is that, when someone visits, one must offer the visitor food; the visitor should decline initially, but then, the host is expected to insist, at which point the guest is expected to accept the invitation and to thank the host for his or her hospitality. This interaction is imbedded within all sub-cultures of Saudi Arabia, and each sub-culture uses its own phrases. In the *Hadith*:

Abu Hurairah (may Allah be pleased with him) reported: Messenger of Allah said, 'When any of you is invited to a meal, he should accept the invitation. If he is observing saum [fasting], he should supplicate for the betterment of the host and if he is not fasting, he should eat'.

This interaction is challenging for people with Parkinson's and their families. The challenges that the people with Parkinson's faced during meals decreased or diminished their natural urge to participate in these interactions. The carers also felt embarrassed that they could not offer their guests food or could not strongly insist that visitors stay when they initially decline; this put them in an awkward position. One of the carers described himself as being caught between two hard places:

Raid: *My dear sister, it is difficult.*

INTERVIEWER: *What is difficult?*

Raid: *All of it. Living normally.*

INTERVIEWER: *Can you explain more so I can understand?*

Raid: *They [referring to his relatives] come to our majlis, and you can see that they feel awkward around my father and that they don't want to stay... but I have to offer*

them food... you know, because my father can't do it because of his speech; he should be the one doing it [offering food], but when he can't, I have to do it; but when I tell them to stay and they still get up to leave, I don't insist that they stay. I know it is wrong, but I don't want them to eat with us and embarrass him, so I become quiet; this is very embarrassing to me and my brothers.

INTERVIEWER: *Why is it embarrassing?*

Raid: *You know... because we have to insist that they stay and we don't. It is shameful.*

INTERVIEWER: *Why is it shameful that you did not insist?*

Raid: *That is our way! You know it... we have to make sure that they eat with us, we have to tell them to stay and swear... it is part of our life ... it is very shameful that someone would visit you and they don't eat your food.*

The social norm is that the person being visited (the head of the house) must insist that the guests stay for a feast; however, it was obvious from the interviews that families with people with Parkinson's did not want to continue with this custom. The eating habit changes of the person with Parkinson's created situations in which both the people with Parkinson's and their families felt embarrassed about how they ate and, thus, did not want their relatives to witness it. In addition, shame was brought on the family for not participating in eating traditions that bring honour to the family.

In addition to issues related to *Silat-ur-Rahim*, the people with Parkinson's suffered other challenges related to their own needs to visit and be visited, which were affected by the changes to their eating and drinking. For example, one male with Parkinson's declared:

Abdullah: *I don't want anybody to visit us now.*

This declaration suggests that now that he has Parkinson's, he does not want anyone to visit his family. This also shows the collective nature of visits. Another male with Parkinson's revealed more details of how life has changed:

Khaled: *No, not anymore... the visits are not like before. I don't know when was the last time I saw them [relatives] ... it is better this way.*

Another person with Parkinson's mentioned how the changes to his eating made him isolate himself:

Naisr: *It is difficult and messy, sitting and eating with all these people, and I am like this (showing me his hand)—difficult. No, no need. One stays in his house better (referring to himself) (smiling).*

Another person with Parkinson's said:

Abdulrahman: *If it was up to me, I wouldn't let them come, but I can't tell people not to come. I am their uncle and the head of the family... they and their sons must come and visit and eat. I don't want to, but I can only give my complaint to Allah... I don't want those kids to see me when I don't know how to eat!*

This statement shows the social constraints that this man with Parkinson's has to endure because of his status: He is the leader of the tribe or the highest figure in the family, but he is not happy being seen by others struggling with his meal—or, as he called it, not knowing how to eat—however, he felt that there was nothing he could do.

To summarize, this theme encompasses the impact of eating and drinking changes on those related to the people with Parkinson's: the impact on the carers in all aspects of their lives, the burden of care as well as their social life. It also shows the impact on other members of the family. The extended Saudi family with its close relationships with the relatives appears to be affected by the changes in eating and drinking. It is obvious from this theme that due to issues with violating social norms, decreasing visits or shortening them was the way families could cope with the changes to eating and drinking. The bigger picture of the Saudi culture and the influence of country regulations on these changes will be explored next.

4.5 Theme three: I leave it all to Allah (Religious, Cultural and Health Service Policies)

4.5.1 Ibtala

Ibtala was mentioned (or referred to using a religious phrase) in both the interviews with people with Parkinson's and their carers. *Ibtala* is an Islamic concept that is widely used by Saudis when discussing their health; it means *hardship* or a *test of hardship*. It is part of the Islamic teaching of how Allah tests a true Muslim, asking, 'How do we, as Muslims, receive a test (whether it is a disease, a loss of a loved one, or a financial crisis)? Do we accept it, or do we get angry and question Allah's test?' According to *Ibtala*, acceptance shows true faith in Allah.

Not all participants used the term *Ibtıla*; however, some used phrases and sentences that still expressed their belief in the concept. For example, when asked about changes that occur along with Parkinson's, Mohammed, a man with Parkinson's, stated the following:

'Allah gives, and Allah takes . . . and we can only say "Alhamdulillah" and be patient'.

Rashid, the son of a woman with Parkinson's (Fayza), was more explicit:

'This is an Ibtıla from Allah, and we are believers . . . Alhamdulillah . . . Allah will make things better'.

Rashid used the term *Ibtıla* in conjunction with identifying himself and his family as believers, stating that *Ibtıla* is a test and that they accept it. He also made his confidence explicit, stating that Allah would relieve him and his family and that their hardship is temporary. It might be that this family's belief in *Ibtıla* and their status as believers plays a role also in the way they deal with Parkinson's. Since Saudi Arabia is a religious country, people strive to show that they abide to Islamic teaching and that they are good Muslims.

Manal, the daughter of a man with Parkinson's (Abdulaziz), was asked about the changes that she perceived her father to be going through by replying with three Islamic phrases typically used when people are in mourning or after having heard sad news:

'Alhamdulillah, to Allah we belong and to Him is our return, there is no strength nor power except Allah.'

Her reply indicates that she views the changes in her father as a test from Allah and that she submits to this test because she believes in Allah's strength to change things back or give her the will to cope with these changes. Conversely, Saud, a male carer, said the following:

'Alhamdulillah it is not something dangerous like cancer'.

Here, Saud expressed relief that his mother's diagnosis is not cancer, and he is grateful to Allah for this 'small test'. The concept of *Ibtıla* re-emerges when questions were specific to eating and drinking changes and the impact of these changes on the lives of both people with Parkinson's and their carers. When discussing eating and drinking changes, Mohammed shared what his usual reaction to these changes was:

'What do I do? Nothing . . . I do what I can . . . I am patient, and I leave it to Allah'.

When faced with *Ibtla*, Mohammed does not seek help; he surrenders and waits for Allah's intervention. Further, Hadeel, the daughter and carer of a woman with Parkinson's, Aisha discussed talking to her mother about eating and drinking changes and the embarrassment and other emotions that her mother feels because of them:

'We don't talk about this subject . . . I mean, she is not happy about it . . . but she is leaving it to Allah'.

This carer believes that her mother chooses not to seek help but rather wait for Allah to ease her hardship. Another daughter and carer of a woman with Parkinson's stated the following:

Amal: 'When she gets upset and fed up, she refuses to eat, and I have to then remind her about Allah and that he chose her, and this is Ibtla, and all that . . . We [the carer and sisters] want her to cooperate with us so she can eat . . . Allah, help her, and help us, too!'

This daughter uses *Ibtla* in a positive way to counsel her mother and remind her that she was specifically chosen for this test. The daughter also informed me that it is not only her mother going through the test but also the family; she prays for all of them.

It is important to note that Saudi families may not be used to discussing their diseases or how to cope with them and the changes that that occur as a result. As mentioned later in the chapter, there are no support groups in Saudi Arabia for people with Parkinson's or their carers, and so neither has the opportunity to discuss Parkinson's with other people having similar experiences.

4.5.2 Transportation

Although the interviews were focused on eating and drinking changes and the impact of these changes, they also explored the challenges that carers face, especially when the carer attempts to fulfil familial and social obligations and to provide care for the person with Parkinson's.

As previously mentioned, the largest group of carers consisted of daughters. In some of the interviews with sons, based on their statements, their sisters appeared to be the main carers of their parents. However, restrictions are enforced by Saudi Arabia on the mobility of females; for example, women in Saudi Arabia are not permitted to drive cars. This cultural barrier appears to be a challenge that is faced by some of the people with Parkinson's and their carers. One female carer explained:

May: *'We have to wait for one of the boys [the brothers] or call a taxi'.*

Further, a male with Parkinson's said the following:

Abdulaziz: *'One of the boys [the sons] can bring me to the doctor, but she [the daughter] has to come . . . She knows what to say to him'.*

This type of cultural barrier for female carers adds to the impact of Parkinson's on carers. The following quote shows how the same cultural barriers affect how these families cope with eating and drinking changes:

Manal: *'No one brought us for Khaled's [the SLT's] appointment, and I couldn't go to get his powder [thickener for her father] by myself . . . One of the boys [the brothers] had to go and get a new appointment, and then we had to wait to see Khaled so he can write for us a prescription'.*

I asked her what she did without the thickening powder, and she replied the following:

Manal: *'I didn't do anything . . . I try to give him small sips of water . . . and tell him to drink slowly, but he still coughs . . . I called all the pharmacies around us, and they don't have the powder. We have to get it from here [indicating the clinic at KFMC]'.*

This carer struggles because she must rely on others to take her to her father's appointments. This transportation barrier causes additional burdens and affects the degree to which she is able to follow the SLT recommendations. It is also important to note how difficult it is to obtain an appointment with a SLT, which will be discussed later in this chapter.

4.5.3 Gender segregation

An unexpected topic discussed in the interviews surrounding the context of Saudi Arabian culture was the segregation between sexes. In many homes around the country, there are separate sections for males and females. On this topic, one person with Parkinson's stated the following:

Mansoor: *'It's not the same . . . When they [guests] eat with us, I have to help myself . . . very hard . . . For lunch, it is different . . . May [the daughter] is with me, and she can't be with me when I have guests'.*

May, a daughter and carer from a tribal community, and her father with Parkinson's, have certain statuses in their tribe. May explained how the family has many visitors because of her

father's status. Most of the time, he sits in the male section of the house, which makes it difficult for her to perform her carer duties. Her father's swallowing problems are being tracked by his SLT who has restricted him from drinking thin liquids. May further stated,

'He sits in the Majilis, or if the weather is good, he sits in the Hosh,²¹ and the door is, of course, always open, and our uncles and cousins and their sons are always coming and going . . . I don't know what he is doing or if anybody is helping him or not'.

She also said the following:

'They [the brothers] ask for coffee, and I don't know if he [father] drinks it with the men or not'.

When I asked if she could obtain help from her brothers, she replied,

'It is difficult for them to say anything for him in front of the men . . . and, to be honest, I don't think they know if he drinks or not . . . He sometimes just keeps it in the cup, and sometimes he drinks it'.

After a pause, she added the following:

'When I am in the kitchen, I hear his cough . . . I know he drank something . . . I know how it [the cough] sounds when he drinks'.

The case of May and her family demonstrates that gender segregation when the family has guests, along with the frequency with which people with Parkinson's receive guests due to their status, decreases the interaction between the person with Parkinson's and their carers, presenting a challenge for following SLT recommendations.

4.5.4 Understanding Parkinson's and the changes that accompany it

One of the issues that people with Parkinson's and their carers mentioned are social perceptions of people with dietary restrictions in Saudi Arabia and people with special needs in general. One woman with Parkinson's shared the following thoughts on the subject:

Aziza: No, I don't go as I used to . . . On the contrary, the girls are very nice; they bring me a tray and make sure I have everything on the Sufra, and they bring me a

²¹ Hosh is part of the house that is outdoor (back/front yard) and used for sitting

spoon and everything, but I don't like it when the others look at me. But I pray for the girls; they are trying to help me.

Although she is thankful for how nice the people in the social gathering are to her, making sure she is served all the food, it is obvious that the extra attention is not wanted. The same person with Parkinson's later said the following:

Aziza: When we are finished and sit for tea, the women start talking about this person who now can only be fed through a tube in his nose or that person who has a tube in his stomach, and that I should be thankful to Allah that I don't need a tube to feed. I am thankful! But this [the talk] upsets me, and I don't like to go any more.

This quote demonstrates how this community deals with, and reacts to, seeing dietary changes and how they tell stories about people who are in worse condition than the person with the problem. Based on this quote, the way this group of women dealt with the knowledge that someone they knew was facing dietary changes caused the people with Parkinson's to stop engaging in these social gatherings. Similarly, a carer for a person with Parkinson's with aspiration and penetration problems stated the following:

Sameera: She once choked on a piece of a sweet, one they serve with tea, and she had violent coughing, and everyone started to hit her on the back and brought water and made such a fuss! She was so embarrassed, the poor thing, she started to refuse anything they served when we went out.

The reactions to her choking of those nearby caused the people with Parkinson's to stop eating altogether at social events, although this same carer explained later on that her mother stopped going out, as well.

Part of understanding Parkinson's is knowing it is a medical condition that needs to be investigated by a medical team and can be managed by many things including rehabilitation, but seeking medical attention appeared to some of the people with Parkinson's to constitute resistance to the will of Allah and a rejection of their *ibtilah*. Because the concept of rehabilitation is also difficult for many Saudi people with Parkinson's to understand, they resist it even more. To them, rehabilitation is something new and strange, and they may feel guilty about seeking services since it could be construed as challenging the will of Allah. As one person with Parkinson's said,

Nasir: *I take whatever they give me... They said, “You need pills”, so I take them every day, and they said I need X-rays, so I did it, and it didn’t do any good. I went to that girl for the [swallowing therapy] and nothing happened... Alhamdulillah, I did everything, but this is what Allah wants, and this is my health.*

This male with Parkinson’s —who (I discovered from the medical records) only attended one assessment session at the swallowing clinic and did not attend any of the follow-up sessions—demonstrates several factors: a) he believed that he had sought adequate medical attention and that he did not require more; b) he believed that X-raying was part of the treatment and not a diagnostic tool (from my experience as a speech therapist, this is a common belief among the older people, who often expect that they will get better once they have left the X-ray facility); and that c) his fate was sealed: Allah had given him this condition/Parkinson’s, and he should accept it and not resist it.

4.5.5 Health Service Organisations and Availability

In Saudi Arabia, medical and rehabilitation services are centralised in three main cities (Riyadh, Jeddah and Khobar); in recent years, some specialised services have been spreading to other cities. For example, there are neurological services, which are specialised medical services provided in particular hospitals or centres; however, accessing them is not a simple or fast process. This is a problem worldwide, especially in countries where health care is free, such as in the UK or the KSA. However, unlike in the UK, the patient has no access to other services. For example, in the UK, there are GP services near patients’ homes, and there are no long waiting times to see doctors. This is not the case in the KSA. Few GP services are available in Saudi Arabia, and obtaining referrals to neurological services is difficult. This lack of services also prolongs the time that the patients wait to access medical necessities like medication. Further, SLT services are only available in the three major cities of Saudi Arabia. Therefore, there is a high demand for these services. As a result of this high demand, many of the hospitals that have SLT services have changed their service policies to only cover assessments and consultations; no intervention speech therapy sessions are available. This restricted access to SLT services was referred to in the interviews, as it adds to the challenges that families of people with Parkinson’s face. One carer explained the problem as follows:

Rashid: *‘It took a long time until we had an appointment with Khaled [the SLT]; actually, we only went to him after the doctor referred us, and then my mother, may Allah forgive her, made us miss the appointment, and when we went to make another appointment, they told us, “We will call you”, as they didn’t have any appointments . .*

. We did go to him, and he did an X-ray, and he[SLT] gave her [mother] food to eat while she was in the X-ray machine, and then he told us what we should let her eat and what we shouldn't, and he gave us another appointment in a few months to check on my mother, but my mother wouldn't go to him. I told you, she is very stubborn . . . He told us not to give her water, I think, to cook the food so it is smooth... I think that's what he told us (smiling). It is a long time ago . . . This was maybe around a year ago'.

In this interview, the son and carer of a person with Parkinson's explained that the process of referrals and the long waiting times to be seen by the SLT had an impact on the services this person with Parkinson's received. The policy of the institute where this patient sought service dictated that patients could be seen only for assessment and counselling services, which also impacted how he received these services. This carer could not remember the recommendations of the SLT, although they appear to be important, as the patient was restricted from eating certain types and consistencies of food, and SLTs do not restrict patients from specific types or consistencies of food unless they are not safe for the patient to consume. On another note, a different carer, a daughter of a person with Parkinson's, touched on of the issue of centralisation of services:

May: 'They [the SLT clinic] gave us an appointment and told us that they would work to help him [father] with his problem, but after only two sessions, he wouldn't go to them; he said it was such a long way to come from our hometown for these sessions'.

The person with Parkinson's, in this case, lives about 3 hours away by car from Riyadh, and this distance was the reason he stopped going to the SLT clinic. Further, on accessing SLT services and information. One carer stated the following:

Huda: 'Khaled [the SLT] told us what is allowed and not allowed to eat . . . He had this problem for a very long time, but we never took him to a SLT; we didn't know about them [SLTs] until the doctor told us'.

Another carer and son said the following in response to a question about SLT services:

Yousef: 'No, we didn't go to anyone, and we don't mind to going to them [SLT services] if there is anyone that can help us'.

Patients access SLT services by referral from specialised medical services, like neurology. Patients have to wait a very long time to access these specialised medical services, which

consequently prolongs the time spent waiting for SLT services. On this subject, the following was stated:

Raid: *'We sent the papers to you [KFMC] and we sent to Faisal [King Faisal Specialist Hospital] and the Guards [National Guards Hospital], and all rejected him . . . Then, one of our relatives, may Allah bless him, took his papers to the doctor [a neurologist], and they accepted him, and now he has a medical file with you [KFMC] . . . I think it took us around two years or maybe more until we knew that what he has is Parkinson's . . . As long as we are finally here [KFMC], things are good . . . They [the doctors] prescribed him his pills, and now he has improved a lot. His tremors are fewer, and he can sit better and even sleep better'.*

When asked about eating, the following was stated:

Raid: *'Yes, everything is better; that's why, now, he can hold the spoon like I told you. He is still not steady, but at least something is in his mouth (laughing)'.*

A daughter and carer of a person with Parkinson's expressed the same thoughts in a different way:

Huda: *We didn't expect that this cough was because of his Parkinson's; we thought he had a problem with his throat. He used to cough and cough . . . No, we didn't tell him [the neurologist]; it never came to our minds that this is a part of Parkinson's. We thought Parkinson's is unsteadiness, tremors, things like that; it has nothing to do with coughing . . . The ENT, because we went to an ENT, told us we should tell the neurologist, and he will send you [the person with Parkinson's and his family] to SLT clinic . . . No, the ENT didn't refer us . . . We went to a private ENT, a clinic near our house, and he is the one, may Allah bless him, that told this is part of Parkinson's, and then Dr Jawad referred us to Khaled . . . He is amazing, may Allah bless him and his family; he explained everything to us like how Parkinson's affects eating and how to help him eat'.*

This narrative provides a view on health services in the country and how the organisation of these services prolongs the suffering of the people with Parkinson's and the burden of the carer. The neurologist did not ask the patient or the family any questions related to the patient's eating abilities, and he apparently did not explain to them the extent of Parkinson's symptoms and what could be affected in terms of the ADLs. The family, due to their limited knowledge of Parkinson's, did not ask about the coughing and did not associate dietary

changes with Parkinson's. Further, the family opted to go to a private ENT clinic and then ask the neurologist to refer them to an ENT, as a private clinic is much easier and faster to go to than a hospital ENT clinic. This process resulted in an additional financial burden on the family. However, the additional burden and delay would have been unnecessary had they possessed the knowledge to ask the neurologist about the coughing or if the neurologist had asked them about changes in the patient's eating habits or swallowing ability.

The medical services that deal with Parkinson's in Saudi hospitals do not have clear processes or policies on how to counsel patients and their families on changes in the patient's dietary habits or swallowing ability or on referrals, as demonstrated by the following response:

Abdulaziz: 'My son told the doctor to refer us to Khaled [the SLT], the one for the throat. We heard about him in the waiting room; the old men were talking about him, and they said he was good and nice'.

The waiting room, as a source of information and networking, was mentioned again by a daughter and carer of a person with Parkinson's:

Amal: 'I met a few girls in the waiting room. They were really nice, and they all had mothers with Parkinson's; we took each other's numbers, and we made a group on WhatsApp. We post any new information we get on it'.

Clearly, people with Parkinson's and their families have the desire to attend support groups. However, there is no Parkinson's support group in Saudi Arabia, nor is there a website for people with Parkinson's to access information in Arabic.

The difficulties and delays in accessing medical or rehabilitation services while the person with Parkinson's struggles with dietary changes can impact the people with Parkinson's in ways that could be drastic:

Manal: 'He [the carer's father] was hospitalised many times. The last time he stayed a week, it was because of his chest, and the swallowing specialist came to us while he was in the hospital and told us he should not drink liquids because they were going into his chest, and he gave us a powder to add to the liquids . . . He, since then, didn't need to spend any nights in the hospital; maybe this is because of the powder or something else. Allah only knows'.

On examining this patient's records, the researcher found that, in his last hospitalisation, the diagnosis was pneumonia, which might have been the reason the neurologists referred him to

SLT services while he was in hospital. The SLT note indicated that the patient had an MBS done, and he was aspirating significantly on thin liquids and had mild to moderate penetration on nectar-thick liquids. The recommendations were to restrict the patient from thin liquids and to dispense thick-it thickening formula.

Accessing specialised medical services and SLT services in a timely manner would decrease the risk of pneumonia, which is the leading cause of death for patients with Parkinson's (Akbar *et al.*, 2015). The issues discussed in the interviews point our attention to the fact that Saudi people with Parkinson's probably visit the SLT (when needed) very late due to the country's health service policies and due to the limited accessibility of these services.

4.6 Summary

The findings of this study show the overall challenges that a person with Parkinson's and his/her carer face with eating and drinking changes. The three main themes and subthemes presented in this study encompass the perceived changes and their impact on the personal, family and social life of the person with Parkinson's as well as on his/her family.

There are many factors that contribute to the way people with Parkinson's deal with eating and drinking changes and the way they accept and engage with rehabilitation programmes such as SLT services. These factors include cultural traditions, Islamic beliefs, knowledge and understanding of their diagnosis as well as the country's laws and restrictions.

In the next chapter, these findings are reflected upon and discussed in relation to the existing literature and its implications. The process of the research will also be further discussed.

Chapter 5. Discussion and Conclusion

5.1 Introduction

The aim of this study was to understand the perceptions of eating and drinking changes experienced by people with Parkinson's in Saudi Arabia, as well as the impact of these changes on their lives and the lives of their families. To that end, this research sought to address two specific questions: What are the experiences of eating and drinking changes among people with Parkinson's in Saudi Arabia? And how do these changes influence the lives of the carers and families of people with Parkinson's in Saudi Arabia?

The study employed a phenomenological approach with the aim of providing a rich contextual description of these experiences in the Saudi Arabian context. More specifically, this study has provided a detailed description of how people with Parkinson's and their carers live through the experiences of eating and drinking changes. It also helped to show their perceptions of how these changes have impacted their personal and social lives, as well as the associated psychological burden for all of those involved. The focus group helped to show another side to the experiences of people with Parkinson's and their carers, including, specifically, how they deal with the medical and rehabilitation management of these changes and the issues SLTs have with their patients when working within Saudi culture.

These major findings are discussed in this chapter, with the aim of achieving a more comprehensive understanding, particularly in the context of the wider literature dedicated to these issues. More specifically, this chapter discusses the findings of the study and describes their contribution to current knowledge on the impacts of eating and drinking changes on people with Parkinson's and their families in general.

This chapter reviews the findings from a cultural perspective to facilitate an understanding of the relationship between Saudi Arabian culture and how people with Parkinson's perceive the eating and drinking changes they experience and the impacts these changes have on their families. From a theoretical perspective, this will support an understanding of the behaviours of people with Parkinson's and their carers with regard to their attendance at SLT sessions and their compliance with SLTs' advice.

This chapter also presents a personal critical reflection of the study as a whole, since the researcher's insights are a useful addition to this qualitative research. The researcher is an

important tool for analysis in qualitative research; therefore, the reflections and perspectives of the researcher are very important when interpreting results (Lincoln & Denzin, 2008). The strengths and limitations of this study, as well as recommendations for future research, are also provided. The last part of the chapter will be the conclusion of this study.

5.2 Reflections during the analysis

In analysing the data produced by this study, the data were revisited and reviewed multiple times in order to better appreciate them from a more holistic and deep perspective. The themes and subthemes were further studied to better understand the differences and similarities between this study and similar studies conducted in the West. Upon reviewing the findings and listening to the interviews, it became clearer to the researcher that the Saudi Arabian culture was overarching in nearly all the data and that there were three cultural elements that spread across all themes with a strong, yet indirect presence. Specifically, family, gender role and religion were the three prominent cultural features identified when discussing eating and drinking changes with both people with Parkinson's and their carers. While these three underlying issues were prominent in the interviews with both people with Parkinson's and their carers, they were not as prominent in the SLT focus group. The researcher's discussions with the participants nearly always involved religious phrases and discussions of the issue in relation to other family members and within cultural norms of eating and drinking, the traditions and practices of receiving guests, and the roles of family members within different Saudi cultures.

5.3 The imprint of Saudi Arabian culture on perceived eating and drinking changes

The changes in eating and drinking were analysed as they were expressed by the participants, their carers and their SLTs. In this section, I reflect on the influence and involvement of Saudi Arabian culture in relation to the major themes of the study: the experiences of people with Parkinson's and their carers, the role of gender in these experiences and, finally, the role of religion.

To begin, it is important to discuss the social norms to which people in Saudi Arabia adhere during mealtimes. Social norms are social phenomena that are circulated within a group through communication (Lapinski and Rimal, 2005). Research has identified two types of social norms: those within a group (a community or a culture), called 'collective norms', and

those understood by the people, or 'perceived norms' (Lapinski and Rimal, 2005). Collective norms are principal codes that the members of a group set as accepted behaviour, whereas perceived norms are the ways in which individuals interpret the collective norms, which may or may not be correct. The reason for misinterpretation is that social norms are rarely discussed or explained openly (Cruz *et al.*, 2000). Misinterpretations can result in collections of new perceived norms among group members. Collective norms exist on a social level, while perceived norms exist on a psychological level (Lapinski and Rimal, 2005).

Chapter two presented a description of these norms that included how people sit and behave during meals within the family and in formal dining situations, while chapter five discussed the difficulties that people with Parkinson's and their carers report with respect to changes in eating and drinking and the effect they have on compliance with these norms and their impact on all involved. This chapter discusses these issues from a broader perspective, incorporating the reflections of the researcher.

5.3.1 The experiences of people with Parkinson's

All of the participants expressed some degree of eating and drinking changes; however, their focus was primarily on the psychosocial impact of these changes and less on the physiological changes themselves. These findings support those of previous studies showing the psychosocial impacts of eating and drinking changes on people with Parkinson's and suggesting that, when considering the effects of these changes on individuals, it is important to consider people in the context of the societies in which they live. According to the International Classification of Function, Disability and Health (ICF) framework developed by the WHO (World Health Organisation, 2001), the dysphagic symptoms of people with Parkinson's should be understood in the context of the entire eating process.

Because the changes experienced by people with Parkinson's affect their interactions within society, their impact is as powerful and life changing as the impact of physical changes. This supports the notion that a diagnosis can change physiological symptoms into socially related behaviours, while also changing a person's social status (Cockerham, 2013). Interviews with people with Parkinson's revealed the emotional and social changes that happen as a result of changes in their eating and drinking.

Previous studies have examined the impact of Parkinson's on changes in swallowing and other neurological conditions; however, few studies have examined eating and drinking changes, which may differ from changes associated solely with swallowing and dysphagia. The interviews revealed that the term 'swallowing changes' was not sufficient to encompass changes experienced by people with Parkinson's, as it failed to incorporate the acts of chewing, eating, sitting for a meal, and being independent during the eating of meals. The findings of this study provide further support for findings in previous research, which have shown that the experiences of eating and drinking changes in people with Parkinson's can be life-changing for patients, their carers and their families (Plowman-Prine *et al.*, 2009; Leow *et al.*, 2010a; Cereda *et al.*, 2014). Statements from participants in this study ranged from '*It is hard to swallow*' to '*It is humiliating to eat*'. The previous chapters have also highlighted that the impact can extend to the family. This is a starting point from which to view the findings and discuss their implications, while attempting to understand the influence of Saudi culture and the strength of this link with the specific findings discussed. The finding that participants' perceptions are diverse leads us back to the phenomenological position adopted in this study that people experience phenomena in many different ways, including through the filters of different sub-cultures across and within countries.

The interviewed people with Parkinson's reported facing various challenges while eating and drinking. Some reported issues specific to the swallowing mechanism, including coughing, difficulty swallowing pills and prolonged eating time (Ali, Khaled), while others reported difficulties faced due to a lack of hand control affecting their ability to eat in a normal way (Ahmed, Saad). Still others reported issues faced trying to eat and drink in a culturally acceptable way, such as trying to sit on the floor, eating with their hands or drinking coffee from small cups (Abdulaziz, Nasir, Saad). These issues tended to lead to other issues, which caused people with Parkinson's to feel embarrassment, uselessness and isolation.

The findings indicate that people with Parkinson's view the effects on their eating and drinking changes as more socially challenging than physically challenging. Interviewees were more concerned with issues in social situations and with eating with their families than with their health or weight. Some participants did mention experiencing pain while sitting on the floor (Ali and Ahmed) or a loss of appetite (Aziza and Hussa); however, most spoke about the context of the social situations in which eating and drinking occurred, focusing on where and

with whom they ate (Mohammed, Nasir, Ibrahim, Haya, Monira, Abdullah, Abdulrahman, Aisha, Aziza, Khaled, Fayza, Mansour).

Though the described eating and drinking changes occurred at every meal, people with Parkinson's spoke about them within the contexts of their social situations. Specifically, they discussed their experiences of embarrassment and isolation and the challenges posed to their religious practices. Specific cultural situations, such as weddings, which were identified by many as the most difficult situations, were singled out. Many declined invitations, left early (before dinner) or spoke of feelings of embarrassment. Miller *et al.* (2006) reported similar feelings of embarrassment and isolation in relation to dining out (restaurants) and going to clubs; however, neither of these activities is applicable to the population of Saudi older people. This provides additional insight into Saudi culture, in which weddings (and other family events) are considered important events that all individuals, including people with Parkinson's, value and feel are essential to social life. These findings provide a holistic view of all of the factors and issues that a person with Parkinson's might encounter during mealtime. The interviews also shed light on other issues that contribute to the challenges people with Parkinson's and their carers face during meals. These include culturally specific issues, including gender segregation, which this researcher feels is definitely one of the issues that needs to be explored further, given its appearance in more than one interview.

Previous studies have suggested that people with chronic illness, such as Parkinson's, have been shown to suffer from psychological distress, physical pain and the effects of medical procedures. Such findings, when combined with the results of the current study, highlight that the medical view of illness is restricted to suffering and physical pain and has largely ignored the consequences of chronic illness. Charmaz (1983) has explained that people with chronic illness experience a loss of self that their illness causes them to live restricted and isolated lives and that they are burdens to those who care for them. Participants' senses of isolation, embarrassment and uselessness were congruent with the findings presented by Miller *et al.* (2006), who described the psychosocial impacts of eating and drinking changes in a group of people with Parkinson's in the UK. The findings are also congruent with Bramley and Eatough's (2005) study, which found that a woman with Parkinson's felt that her body no longer represented her identity, leading to the creation of a new sense of self that conflicted with how she viewed herself.

The loss of one's previous self seems to be an important factor in the lives of people with Parkinson's. Studies have found that people with Parkinson's do experience a loss of identity when they lose their independence and require help doing things they used to do by themselves (e.g. eating and drinking) (Charlton and Barrow, 2002). The interviews in the current study pointed to an indirect loss of self, as Monera described in her interview about how her role as a mother had changed from cooking the food for her family to not having any say in what to cook. As she noted, now, '*I only see the food [when] they bring it to me*'. This quote shows how Monera lost her previous role within her family and became excluded from deciding what food would be eaten. In other words, Monera became a recipient. Her loss of her role as a mother indicates a loss of herself, as well as a loss of her ability to identify herself as a mother.

In addition to the loss of self, the current study shows how people with Parkinson's also experience a loss of control. For example, participants and their carers were distressed by the need to depend on others for eating and cleaning. These findings are similar to those of a previous study, in which participants were distressed by a shift from controlling their food preparation and eating to being controlled by the food (Hsu *et al.*, 2015). In the same study, this distress was compounded by changes in how participants' families came to perceive them (i.e. as incompetent), suggesting that the family also needs to be considered as a client when it comes to improving the illness experience (Hsu *et al.*, 2015).

In addition to illustrating the importance of the family in considering the impacts of Parkinson's disease, the current study also supports previous findings that people with Parkinson's become less involved in social activities over time and, therefore, become more socially isolated (Soleimani *et al.*, 2014). Social identity theory states that the social group is an important source of pride and self-esteem and that a person's sense of self is largely dependent on the group to which he or she belongs (Tajfel and Turner, 2004). The participants discussed how changes in eating and drinking affected multiple aspects of their lives. The shift from being a useful and valued person in their social groups to losing their independence was a major change that caused distress. Similarly, a study conducted by Stanley-Hermanns and Engebretson found that participants reported feeling watched, criticized and judged

(Stanley-Hermanns and Engebretson, 2010); these findings parallel those of the present study, in which participants were concerned about being the subjects of gossip or the focus of negative attention at events (e.g. due to people emphasizing their difficulties coughing and eating). Social isolation resulting from eating and drinking changes is perhaps best illustrated in the following quote from one participant, '*I don't go... because I can't eat*'. It seems that people with Parkinson's are more willing to isolate themselves during meals than to expose their eating and drinking changes due to their disease. This might be a choice specific to the Saudi culture, since previous research has suggested that overt criticism and an exaggerated importance of appearance are key attributes of the Saudi culture and that these attributes are driven by rigid social codes (Al-Sabaie, 1989).

Ownership of the illness was a theme that comprised various aspects, ranging from '*we all have Parkinson's*' to patients' reluctance to share the burdens of their illnesses with their families. Despite this reluctance, the statement, '*We all have Parkinson's*' shows the impact one person with Parkinson's can have on changing family dynamics and social lives. Participants expressed that the burden on the family was different than that of direct care. They claimed that they should not be the reason for families having to change their social lives or eating practices. Given that the practices of eating at weddings, at other people's homes and at home are so tied to Saudi culture, this reluctance helps explain some of the social isolation that people with Parkinson's experience.

Reflecting on the choice of the words '*not their fault*' and '*my condition*' helps to show this side of the impact of Parkinson's. One participant replied to a question about why his family were not sitting at the table with him with '*No! It is not their fault ... I am the one who has this condition*'. This directs attention to the ownership of Parkinson's and how people with Parkinson's view themselves. Given the constraints of this study, this aspect of the disease has not been fully explored in this research; however, it is recommended that future studies examine the issues associated with the ownership of the disease, including, for example, the guilt people with Parkinson's feel and how they perceive themselves, and whether these things can be easily overcome and in what ways.

5.3.2. Experiences of people with Parkinson's: patients' failure to appreciate the seriousness of their condition and the key role played by Saudi culture

When seeking to understand why many of the people with Parkinson's stopped attending SLT sessions after their first visit, as reported by the SLT focus group, we must consider cultural factors and the failure by those with Parkinson's to understand the seriousness of their condition. SLT sessions are important because they help to track the progress of Parkinson's, which is, of course, a progressive disease, whose perceived and actual severity change over time. SLT sessions aim to help people with Parkinson's and the carers understand what is and is not safe to eat and drink and the consequences associated with eating unsafe foods and drinking unsafe liquids.

The SLT focus group showed that SLTs are concerned with the very low attendance of people with Parkinson's at their sessions. They attributed this low attendance to a failure to understand the importance of these sessions, a failure to understand the role of rehabilitation services, the frequency of these sessions (weekly) and/or the large distances between patients' homes and SLT clinics (which are only available in major hospitals in major Saudi Arabian cities).

Many studies of people with Parkinson's have shown that patients are aware that their disease is chronic and has no cure (Charlton and Barrow, 2002; Schenkman *et al.*, 2002); however, the same cannot be said for the participants in this study. These participants demonstrated little or, in some cases, no knowledge of Parkinson's. This could be due to a lack of education, unsatisfying interactions between SLTs and other healthcare personnel and/or Saudi Arabians' general cultural beliefs regarding aging.

Previous studies of other populations have found that the low incidence of treatment-seeking behaviours among those with swallowing problems was a function of the belief that eating difficulties are a normal part of old age. For example, Turley and Cohen (2009) found that only 22.6% of older people with swallowing problems sought treatment. They also showed that the most common reasons for not seeking treatment were a lack of awareness of the

available treatment options and a belief that the changes experienced were due to old age. Similarly, the current study found that limited knowledge about SLT services was a major reason people with Parkinson's failed to attend these services. Many of these people also attributed their changes in eating and drinking to old age. For example, in talking about changes experienced, Naif stated, '*With age...everything becomes damaged [smiling], like an old car...you're walking, then you're sleeping...then you're eating...one day nothing works...we say Alhamdulillah.*'

The findings of this study also showed that people with Parkinson's failed to attend swallowing treatment sessions even after being consulted about their importance. In the focus group, the researcher asked the SLTs what they spoke about and did during their initial patient interviews. The SLTs responded that they discussed patients' case histories, assessed the patients, discussed diagnoses and treatment plans and stressed the importance of returning for subsequent treatment. All of the SLTs agreed on the importance of telling patients that they must attend a follow-up session. However, this seems to have little or no effect on patients' return behaviours, given the poor attendance rate at SLT sessions.

Cultural reasons could contribute to this low attendance rate. Saudi Arabian patients may experience difficulties dealing with healthcare professionals because many are only familiar with their family members and because hospitals are strange environments for them. As the example given by participant K in the focus group illustrates, whilst patients may feel comfortable telling their family members what they can and cannot eat, they are unlikely to be as comfortable expressing these opinions to a SLT in a hospital. The patient about whom participant K talked ate the cucumber offered to him by the SLT and did express that it was difficult for him to eat. The patient treated the assessment session as a social visit and did not want to offend the SLT by rejecting the food offered to him.

This example elucidates an important point made earlier: that the current way of recording medical history (asking open questions and expecting the patient to volunteer information) produces serious challenges and/or might not be applicable in Saudi hospitals, given patients' reluctance to provide valuable and/or personal information.

The study findings also raise important questions about the ways in which Saudi patients deal with the foreign and unusual environment of hospitals. The differences between the cultures in which people with Parkinson's live and the foreign cultures of hospitals may explain the level of discomfort patients feel and their unwillingness to attend weekly therapy sessions. It

is unusual for Saudi Arabian patients to have to seek help or treatment in a different cultural setting.

With regard to the terms expressing the community's knowledge of SLT, the participants called their SLTs '*speech therapists*', '*swallowing specialists*', '*the person to whom they talk*', by their first names or '*the swallowing girl*'. Since the title 'SLT' was unfamiliar to the patients, people with Parkinson's referred to their SLTs by the service provided. This inability by the patients to address their SLTs by their proper professional title further illustrates the general lack of knowledge about health care among this population.

Also worth noting is the significant difference between how Western and Saudi societies refer to time. In the West, calendars and clocks are used to measure time, whereas, in Saudi Arabia, time revolves around praying. This disconnect between how the Western health system asks patients to take medication (e.g. at 2:00 pm) and how people with Parkinson's perceive the question (e.g. after *Asir* prayer or before *Maghrib* prayer) may pose challenges for patients and highlight the uniqueness of working within Saudi culture.

5.4. Understanding the main findings in relation to theoretical constructs

Various theories have been developed to account for health-related behaviours. These theories are used in health research to design and develop interventions and needed policies to modify certain health behaviours. Before reviewing some of these theories and testing their relevance to the findings of this study, we need to look back and understand the meaning of behaviours (health behaviours). A behaviour is "*anything a person does in response to internal or external events...behaviours are physical events that occur in the body and are controlled by the brain*" (Michie *et al.*, 2014, p. 36). There are different kinds of health behaviours: those that are necessary for preventing disease, those that concern health and social care, and those that are important for limiting the progress and effect of long-term conditions; these behaviours are needed to, for example, adhere to medical advice and seek medical care appropriately.

Health behaviours are influenced by the physical environment as well as social and cultural environments. Understanding the context in which these behaviours occur is important to subsequently develop intervention strategies that would likely be more effective and implementable (Michie *et al.*, 2014).

The question then becomes: why do we need to consider theories? Utilizing a theory when designing an intervention is essential as it provides a framework to enable the use of the accumulated evidence. A theory can identify what is needed for a behaviour to change and ways in which the intervention can be successful. A theory can construct an intervention framework to modify or change a behaviour (Cockerham, 2013; Michie *et al.*, 2014).

Numerous theoretical perspectives have been proposed to examine and understand how people cope with illness and adapt to the changes that come with illness (Mielewczyk and Willig, 2007; Barker and Swift, 2009). Some theories consider internal processes in which people's knowledge, attitudes and beliefs effect their behaviours (Becker and Rosenstock, 1984; Armitage and Conner, 2000), while other theories focus on how social pressures influence behaviour (Hogg and Terry, 2000; Bendor and Swistak, 2001; Mielewczyk and Willig, 2007; Ajzen, 2011; Cockerham, 2013). This study reviewed some of the most common theories to understand behaviours of Saudi people with Parkinson's with respect to attending SLT sessions and following SLT recommendations. In particular, these theories were applied to reconcile findings from the SLT focus group, which pointed to reduced or non-existent attendance at SLT sessions, and the carer interviews, which suggested that patients struggle to follow SLT recommendations, with interviews showing that people with Parkinson's and their carers feel that eating and drinking changes significantly impact the lives of individuals with Parkinson's.

Michie *et al.*, in their book 'ABC of Behaviour Change Theories', found that just four theories account for more than 60% of articles relative to behavioural theories: the Transtheoretical Model of Change (TTM), the Theory of Planned Behaviour (TPB), Social Cognitive Theory (SCT), and the Information-Motivation-Behavioural-Skills Model (IMB). An additional four theories accounted for 12% of the articles retrieved in the literature search: the Health Belief Model (HBM), Self Determination Theory (SDT), Health Action Process Approach (HAPA), and Social Learning Theory (SLT). Social Learning Theory is a precursor of Social Cognitive Theory. The 'ABC of Behaviour Change Theories' described 83 theories, listed their component constructs, and explained how they could be used (Michie *et al.*, 2014). This section will review some of these theories in relation to the findings of this study.

To begin, the health belief model (HBM) (Hochbaum *et al.*, 1952) is a well-known psychological model that attempts to explain health behaviours by focusing on individuals' attitudes and beliefs (Becker and Rosenstock, 1984). HBM suggests that external and internal factors influence people to act in a certain way regarding health-related behaviours. The

likelihood of a person changing behaviour or participating in a health-promoting behaviour is based on that individual's perceived understanding of the disease and the risk of its consequences. Participants in this study seemed to view the changes caused by Parkinson's as part of the typical progression of old age. Because these changes cannot be cured, they appeared to view them more as a maintenance issue than a medical issue. This finding supports a previous study which found that for people with Parkinson's, 'successful living' means maintaining a usual or readjusted state of health (Kang and Ellis-Hill, 2015). Participants whose Parkinson's symptoms were not severe may have felt successful because their social roles remained similar to those in their pre-illness lives. Those with more severe symptoms may have measured success based on their level of independence and resistance to the worst-case scenario (e.g. physical immobility).

Previous studies have recommended that healthcare professionals compare patients' pre-illness lives with their current lives (Kang & Ellis-Hill, 2015) to examine changes, both physical and psychological, and identify significant concerns for each individual to develop effective, personal treatment plans. Likewise, findings of the current study also suggest that SLTs should identify changes in eating and drinking among people with Parkinson's and not focus solely on a mechanical 'swallowing' perspective. The SLTs in this focus group discussed how people with Parkinson's come to their clinics with different levels of swallowing problems. They also noted problems assessing patients due to the patients' inability to fully understand why they were seeing an SLT and their failure to return after the first visit. When patients failed to return, the SLTs could not ask them about their levels of happiness or their feelings about the SLTs' recommendations.

The SLTs noted that people with Parkinson's first visit SLTs at different stages of the disease; therefore, SLTs see a wide range of swallowing problems. However, at any stage, the patient's compliance and willingness to follow up presents a major challenge regarding tracking patients' progress. The findings of this focus group suggest a need for SLTs to see patients at the earliest stages of Parkinson's, irrespective of the presence of signs of swallowing problems. Such a step would allow SLTs to identify patients' lifestyles, determine what is 'normal', and follow the patients through the progression of the disease. It is important that SLTs also examine changes affecting patients' contributions to normal meals and find ways to reduce the impact of these changes.

The HBM model considers six factors that are believed to predict health behaviour:

1. Perceived susceptibility,

2. Perceived severity,
3. Perceived benefits,
4. Perceived barriers,
5. Health motivation (motivation to engage in health behaviours) and,
6. Cues to action (Armitage and Conner, 2000).

According to the HBM model, a person is more likely to behave in a specific way (e.g. to attend a SLT session or follow SLT recommendations for food restrictions) if the individual perceives the threat of the condition (in this case, Parkinson's) or sees the benefit of doing the behaviour (attending SLT sessions, getting better/not deteriorating further). Additionally, motivation or change in symptoms can help an individual behave in a specific way as recommended by the SLT.

This model is suitable for interpreting some behaviours (or lack thereof) of people with Parkinson's. Although the people with Parkinson's in this study did not directly address the reasons behind their behaviours, the carers' interviews and the SLT focus group provided several insights. In particular, the SLTs noted that people with Parkinson's failed to attend the session because they did not understand the importance of the sessions (in addition to other factors, such as frequency of the sessions and the distance between the hospital and home). Carers also indicated this lack of understanding; they revealed that some people with Parkinson's do not even know that they have the disease. The HBM does not, however, explain the weight of each factor or the weight of the combination of factors. Therefore, there is no clear relation between this model and the findings of the present study.

Another model that might help explain the findings is Sick Role theory (Parsons, 1951), which suggests that ill people do not behave as they once did in society. If such people are not productive, then society accepts their new roles and lowers its expectations of their behaviours (Parsons, 1951). This concept explains the rights and responsibilities of a person who is ill by suggesting that a sick person has the right to be exempted from normal social roles and is not responsible for his condition. The Sick Role concept also holds that a sick person is obligated to try to get well, seek help and cooperate with healthcare professionals. This may present a challenge in Saudi Arabia for people with Parkinson's since these individuals seem to feel that they meet their duty by attending a single SLT visit. Furthermore, the process of rehabilitation (frequency of sessions, patient participation, home exercises) does not seem to apply to patients in this sample. Saudi patients could not be expected to seek medical or rehabilitation interventions, since the findings show that these

patients do not feel obligated to seek help or cooperate with SLTs by returning for additional sessions.

Social constructionism theory (Berger *et al.*, 2002) may also explain why patients do not return for treatments. This theory holds that the social world involves shared assumptions about reality. It is founded on the idea that knowledge is constructed and not created independently from a society's or an individual's experience and argues that humans rationalise their experience by constructing models of the social world. Social constructionism theory views society as existing as both a subjective and an objective reality and recognises knowledge as a set of beliefs in which people can have reasonable confidence. In society, individuals who interact with others have a shared understanding and notion of what constitutes knowledge in their group (Cockerham, 2013). Regarding health and illness, social constructionism proposes that 'scientific knowledge and biological discourses about the body, health, and illness are produced by subjective, historically determined human interests and are therefore subject to change and reinterpretation' (Gabe and Monaghan, 2013, p. 130). This theory helps to explain why the social world of people with Parkinson's in Saudi Arabia deems certain symptoms, such as the loss of an ability to feed oneself, as acceptable, as illustrated by one patient's comment that needing help eating was part of her ageing process and that nothing could be done about it.

The interviews in this study indicate that in some instances, people with Parkinson's do not fully understand that Parkinson's is incurable, the severity of their condition, the dangers associated with choking and aspirating, or even that they have Parkinson's. Regardless of the reason (e.g. information received from the doctor, lack of available information about Parkinson's, or religious beliefs), this lack of knowledge may affect their likelihood of taking action or seeking help.

Some social behaviour theories indicate that a patient's awareness of a disease and its severity are predictors of action. Among these, the most dominant model in health behaviour research is the theory of planned behaviour (TPB) (Mielewczyk and Willig, 2007), a social cognitive model that attempts to explain human behaviour and its link to attitudes and beliefs. TPB suggests that behavioural intentions are shaped by the attitude toward the behaviour, subjective norms and perceived behavioural control (Ajzen, 2011). Intentions indicate one's willingness to perform a behaviour (Barker and Swift, 2009). People's intentions can be predicted by their attitudes, the social norms of their group, their own perceptions of behaviour and their control over their behaviour. Regardless of how a person arrives at a

behaviour, the attitude, social norms, and perceptions of behaviour control all are driven by a person's beliefs (Ajzen, 2011). Clearly, the beliefs of the population in this study affect their perceptions of health treatments and the aging process.

In the literature review, the researcher noted that Saudi culture is heavily influenced by the Saudi interpretation of Islam. Saudi Muslims typically believe that illness is a test of a person's faith in God, and that part of the individual's faith is to believe that all past and future actions are written in preserved tablets. In other words, illnesses and injuries are part of a person's destiny. The findings of this study show that people with Parkinson's and their carers have strong religious beliefs, as evidenced by their use of religious phrases, such as '*thanks to Allah*' and '*it is all in Allah's hands*'. These beliefs often prevent people with Parkinson's from going to their recommended SLT sessions. These observations led the researcher to conclude that Muslims' strong beliefs about pre-destiny might reduce the motivation of people with Parkinson's to seek the help of SLTs, despite SLTs emphasising the importance of therapeutic sessions.

This theory conflicts, however, with reports from both the SLTs and people with Parkinson's regarding patients' attendance at the neurology clinic. In other words, the high number of no-shows in the SLT clinics did not extend to the neurology clinic. This difference could be because SLTs do not give patients anything tangible, like pills, or because Parkinson's medication works quickly and noticeably (e.g. by stopping/reducing tremors, reducing rigidity, minimising pain, etc.). On the other hand, SLT management is a long process where the benefits are not immediately noticeable (weekly therapy sessions). Further research could explain this issue in detail. In general, however, this conflict in attendance between SLT sessions and neurology clinics makes it difficult to apply the theory regarding Muslims' beliefs about pre-destiny. This conflict also makes it a challenge to predict the action of this group of people based on their beliefs, as stated in the theory. Modification or extension of the theory might make it more applicable. Instead of using behaviours as a general term, it might be better to divide behaviours into categories. Specifically, the findings of this study suggest that behaviours can be divided into how people react to interventions requiring long term commitment and how they react to interventions that yield immediate results.

Self-categorisation theory (Turner and Reynolds, 2011) describes the way a person identifies with a specific group. This theory, along with social identity theory, forms the social identity approach. In fact, self-categorisation theory evolved from social identity theory and can be described as a major component of an extended social identity theory (Hogg and Terry, 2000). According to social identity theory, intergroup behaviours are guided by the pursuit of a positive social identity through a positive in-group uniqueness, which is motivated by the need for confident self-esteem (Hogg and Terry, 2000). Bendor and Swistak (2001) discussed how an individual's behaviour is driven by his desire to gain social approval from the group to which he belongs (Bendor and Swistak, 2001). Christensen et al. (2004) employed self-categorisation theory to understand social norms. They stated that an individual's beliefs about what behaviours are suitable and acceptable within a group are connected directly to the individual's self-perception as a group member. Social settings are also a significant factor in how an individual identifies with a group and play an integral role in individuals' self-categorisations as group members (Christensen et al., 2004).

Accordingly, self-categorisation theory can be used to modify the behaviours of people with Parkinson's regarding their attendance at SLT sessions. The situations participants in this study identified while discussing their struggles with eating and drinking were social situations with their own social norms. If a medical facility or SLT clinic can convince people with Parkinson's that SLT sessions are part their typical lifestyle, then people with Parkinson's may come to feel that attending these sessions is a positive social behaviour. To achieve this goal, there is a need to bring together groups of people with Parkinson's, which can serve as nuclei for future support groups that would allow SLTs to demonstrate that SLT sessions are a positive way to deal with Parkinson's. These groups would also enable people with Parkinson's to feel a sense of belonging to a group and to understand that attending sessions (PT, SLT, OT) is part of the normal lifestyle of someone with Parkinson's. In other words, such groups would show that SLT attendance is not only an acceptable behaviour but also a positive one.

A final theory to review is the COM-B model, which identifies behaviours as part of a system that involves other components (conditions). Three essential conditions need to interact for a specific behaviour (B) to occur: capability (C), opportunity (O) and motivation (M) (Michie *et al.*, 2014). These conditions will be briefly explained.

Capability: The physical and/or psychological ability of a person to perform the behaviour (physical strength, stamina, knowledge, skills)

Motivation: The processes in the brain that direct behaviour. A reflective and automatic mechanism activates or inhibits the behaviour. Therefore, motivation includes the processes of evaluating and planning as well as emotions and impulses.

Opportunity: Physical and social environments (opportunities) that enable the behaviour. These are external factors that prompt behaviour, and they include financial resources, time, and cultural environment.

The three conditions above need to interact and influence each other and result in influencing the desired behaviour.

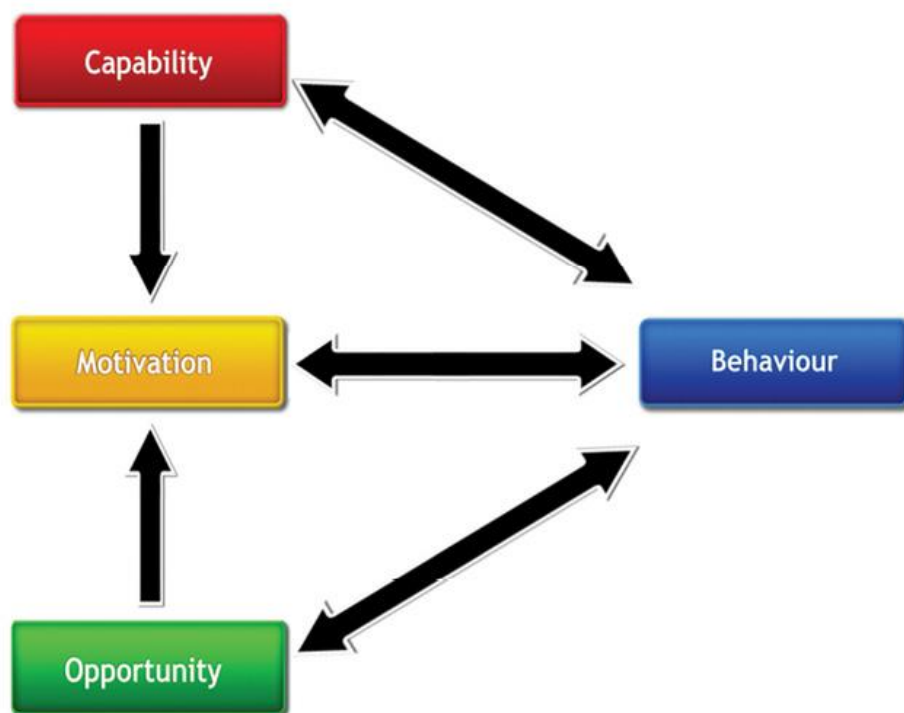


Figure 3 The COM-B model adapted from (Michie *et al.*, 2014).

The COM-B model was developed as part of a larger behavioural system, the Behavioural Change Wheel (BCW), designed to help researchers move from identifying the behaviours that need to be changed to designing appropriate interventions (Barker *et al.*, 2016). The Behavioural Change Wheel facilitates identification of nine intervention functions and seven policy categories. This step is followed by identifying specific behavioural changes techniques and the most likely effective models of delivery (Michie *et al.*, 2011).

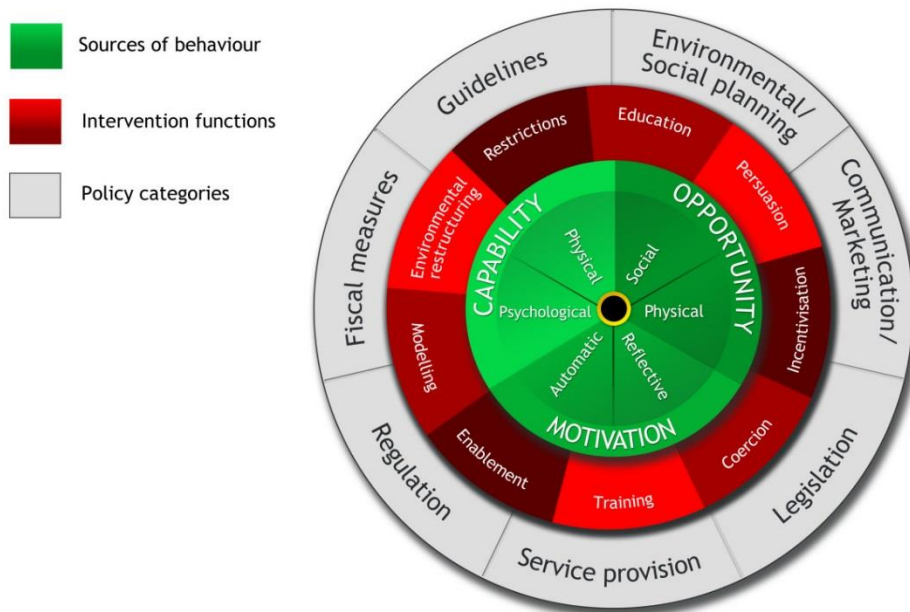


Figure 4 The Behavioural Change wheel adopted from (Michie et al., 2011).

The COM-B model suggests that all physical, psychological and external conditions are relevant, but it might not be necessary to target all the components of the system to change a behaviour.

In some cases, there might be a need to pay attention to motivation (develop positive feedback about change or develop appropriate beliefs); in others, attention should be directed to capability (setting goals or feedback). In some cases, all three components are targeted.

The COM-B model is very clear in that it is crucial to have a clear understanding of the nature of the behaviours that need to be changed or the intervention most likely will not be as effective as needed. This study provides the first step in identifying what behaviours need to change (e.g. compliance with attending sessions and adhering to the SLT’s advice) and some barriers for this behaviour (e.g. knowledge, motivation, cultural barriers, religious beliefs, availability and accessibility of services).

This model will be further explored in section 5.7 as for how it can be applied to the Saudi PwP and SLTs.

5.5. The experiences of carers and the influence of gender

The carer interviews show that carers' social lives are affected by the changes experienced by people with Parkinson's (Asma and Amal). In general, the carers reported feeling sadness (Asma and Sameera), embarrassment (Adel) and an additional burden of care (Manal). The current study supports existing evidence that carers of people with Parkinson's are exposed to signs of distress and issues related to social and psychological wellbeing (Pasetti *et al.*, 2003; Cifu *et al.*, 2006; Schrag *et al.*, 2006; Glenn, 2007; Oguh *et al.*, 2013). One of the strengths of this study is that it shows the complexity of the relationship between people with Parkinson's and their carers. Specifically, the findings show that the primary factors that influence carer-patient relation are gender, sub-culture and country-imposed rules governing men's and women's activities and movements. People with Parkinson's, their carers and their families are all affected by the eating and drinking changes caused by Parkinson's.

Though this research started by exploring dysphagia/swallowing changes, the findings showed that eating and drinking changes also include other acts related to meals, such as feeding and facial cleansing. Many of the carers mentioned having to wipe the mouths of people with Parkinson's or asking the patients to wipe their mouths themselves. Furthermore, the carers' accounts of feeding Parkinson's patients suggest a lack of independence among people with Parkinson's that changes the carer's social experience of eating. Reflecting on this association reveals a broader perspective of the eating and drinking changes caused by Parkinson's by drawing attention to the appearance of people with Parkinson's and to who performs the cleaning. Reflecting on this cleaning process reveals the different sub-cultures of Saudi Arabia and the different ways in which family members are treated. For example, a mother with Parkinson's who experiences her daughter cleaning her face may find the situation so disturbing that it isolates her from the family meal. In a different situation, one daughter-carer said that she felt too uncomfortable to tell her father with Parkinson's to wipe his mouth. The difference between these two situations reveals the importance of conducting social studies to examine the different sub-cultures of Saudi Arabia and the family roles of females and males.

The impact of eating and drinking changes on carers' social lives was one of the themes of this study. The carers expressed that caring for someone with Parkinson's had influenced their social interactions. Studies on carers in general have reported that carers' social lives are often affected by their care (Chambers *et al.*, 2001; Roland *et al.*, 2010). This study agrees with these findings, but also offers a specific cultural perspective. In the literature, the decrease in carers' social

lives has been attributed to the increased burden of care or the decrease in the social lives of people with Parkinson's. The present study, however, has further demonstrated that carer's social lives are affected by Parkinson's because their social lives are highly interwoven with the social lives of people with Parkinson's. This can be attributed to the intergenerational nature of social lives in the Saudi Arabian population. This finding is distinct from the extant literature because it introduces an additional factor affecting carers' social lives. For example, non-married daughters choosing not to go out without their mothers was a major issue mentioned by the interviewees in this study. When a female carer in Saudi Arabia is not married, cultural rules prevent her from visiting relatives without her mother. For example, the carer Dalal described how her mother's eating changes had caused her to isolate herself. This example shows how the social lives of non-married daughter-carers were drastically affected by their mothers' Parkinson's.

Along the same lines, a thematic thread implicit in much of the discussion surrounding the impact of Parkinson's and who is affected by it concerns the gender(s) of the person with Parkinson's and the carer. This thread was supported by the present study, in which gender was a significant factor in conducting the interviews (as discussed further in the limitations section). The SLTs in the focus group also mentioned gender, but typically with respect to the relation between the SLT's gender and that of the patient or carer. In sum, the issue of gender appeared all of the interviews, often in the context of comments about gender segregation or the relationship between the gender of the carer and that of the person with Parkinson's.

One example of how gender affects the carer's role arose in the theme of '*challenges to eating with the hands*'. One female carer explained how, even though her father's hand tremors caused him to '*make a mess*' on his face, she chose not to take action because, as she stated, '*he is your father*'. This reflects the role of a father as a figure demanding respect in some Saudi Arabian cultures. The histories of both the Kingdom and different Arabic tribes, all of which have been led by men, strongly influence this familial dynamic. Often, understanding tribal life styles is integral to understanding the behaviours of certain Saudi families.

Another pertinent example of the effect of gender was described by one daughter-carer who is unable to wipe her father's mouth or ask him to wipe his mouth for fear of being

disrespectful. The result was that the father was left with a messy face. This situation could be attributed to the carer's gender, since some Saudi Arabian cultures limit the behaviours of females in their homes. Such a cultural limitation may have prevented the daughter-carer from notifying her father about the mess on his face. The daughter-carer may also have held her tongue due to gender segregation, since some homes have separate sections for females and males. In such a household, it would be unusual for a daughter-carer to eat with her father on a daily basis, as would be expected in a 'normal' family situation. Regardless of the interpretation, this daughter-carer's experience reveals important information related to answering the research question. If this were a social study, a follow-up interview would have been helpful for understanding the reason behind the carer's experience.

Another pertinent example of the effect of gender on Parkinson's care was illustrated by one daughter-carer's statement: *'I am the girl [the daughter]! I am the one that is caring for my father'*. This comment reveals the relationship between gender and expectations about the carer's role in the family. From this daughter-carer's perspective, it was her gender, rather than other factors (e.g. her age, living situation or birth order) that dictated her role as a carer.

Although there are no publicly available studies examining carer genders in Saudi Arabia, studies on other issues have illustrated the limited role of females in Saudi Arabia. For example, physical therapy research in Saudi Arabia has recognised the limitations imposed on Saudi females and found they have restricted movement outside their homes, suggesting that different treatment plans are required for male and female patients (Al-Eisa, 2010). In addition, a comparison of Saudi women's physical activities with those of women from other countries showed that Saudi women's physical activities were limited. This was attributed to the male-dominated social structure of Saudi society, in which women may develop lower internal senses of control and lower confidence levels (Al-Eisa and Al-Sobayel, 2012). Still other studies have suggested that the male dominance prevalent in Saudi Arabia may stem from the country's history of restricting educational opportunities for women (until recently) (Mobaraki and Söderfeldt, 2010) or from tribal communities, which have influenced the country's culture towards conservative initiatives and customs (Alajmi, 2001). Along these lines, the findings of the present study reveal that, while eating and drinking changes among Parkinson's patients caused female carers to withdraw and isolate themselves, similar behaviours were not reported by male carers (except when discussing family activities

involving the people with Parkinson's). These findings, when considered in light of prior studies on the current situation of females in Saudi Arabia, reveal new information about females' abilities and struggles related to fulfilling their roles as carers.

Unlike many of the studies conducted on informal carers in the West, which have focused either solely (Thommessen *et al.*, 2002; McLaughlin *et al.*, 2011) or mostly on spouses (Oguh *et al.*, 2013), this study found that spouses formed the smallest group of carers (only one wife), while daughters formed the largest group. In Spain, Martinez-Martin *et al.* (2008) found that most of the carers in their sample of 289 carers were women and that 75% of the carers were spouses, while in another study in Brazil (Carod-Artal *et al.*, 2013) revealed that 88% of the 50 sampled carers were females and that 78% were spouses. The 2010/2011 Canadian Community Health Survey showed that the primary informal caregivers of people with Parkinson's tended to be spouses (64%) and female (62%) (Wong *et al.*, 2014). In contrast to these Western studies, the present study found that, though carers in Saudi Arabia also tend to be females, daughters are the main carer group. However, the present study agrees with previous findings in showing that daughters experience the highest burden among all carer groups, suggesting that the pressure on daughters is similar across countries, regardless of culture (Chappell *et al.*, 2015).

The issue of the burden of care on daughters reveals another insight from the interviews related to the ties among family members of people with Parkinson's. In one of the carer interviews, the relationships among sisters were affected by the added burden of their mother's Parkinson's and the need to cook for both the family and the mother because of the mother's eating and drinking changes. This is an important finding because it shows the impact of eating and drinking changes on the relationships among family members. The additional burden of cooking for the mother with Parkinson's caused friction between the sisters, highlighting the impact of Parkinson's and its symptoms and changes on the whole family. It is important to mention that the topic of cooking was mentioned by only one daughter and one female with Parkinson's, even though, in Saudi culture, cooking is the sole responsibility of women. Furthermore, in homes with adult daughters, the cooking is usually done by the daughters, with minimal involvement from the mother. The presence of affordable live-in domestic help also reduces the mother's cooking activities. Nevertheless,

there are still families in which mothers are responsible for cooking, regardless of their socioeconomic situation.

It is interesting that cooking, with its close ties to care and eating and drinking changes, which has been mentioned in the literature as a challenge for people with Parkinson's with swallowing problems (Andersson and Sidenvall, 2001; Miller *et al.*, 2006), was not mentioned frequently in the current study. It may be that the daughters did not report changes to cooking patterns because they inherently accept such changes, or it may be that daughters decided not to mention these changes because it is not socially acceptable for females to complain about such burdens. This finding could be related to the theory of planned behaviour and how it can explain the roles and behaviours of carers within Saudi culture. Future research should consider the carer's role further, possibly by developing questionnaires for carers that address the burden of care and tasks related to mealtime (including cooking). It may be easier for carers to fill in questionnaires than to talk openly about the difficulties involved in taking care of their parents.

The gender of people with Parkinson's was also a factor associated with the impact of eating and drinking changes. For example, Dalal noted that her mother was concerned that her husband's view of her might change, leading him to marry someone else. This might be a fear specific to the Saudi Arabian culture, which allows polygamy. A case study by Bramley and Eatough (2005) may help to explain the thinking process of a female with Parkinson's in this situation. Bramley and Eatough (2005) found that Parkinson's can have a negative impact on feelings of femininity. In their single-case study, the participant shared being conscious of people staring at her (Bramley and Eatough, 2005). This finding supports Dalal's description of her mother and agrees with the study by Fleming, Tolson and Schartau (2004), which explored the experiences of women with Parkinson's in relation to their womanhood. The women interviewed by Fleming, Tolson and Schartau reported changes in their relationships with their partners and with their families and also reported experiencing isolation (Fleming *et al.*, 2004). The present study might extend these findings by explaining the link between the changes in eating and drinking experienced by people with Parkinson's and the overall changes in their emotional and social lives.

It is important to note that female-related challenges were not the only gender-specific issues raised in this study. Several issues related to the male gender also need to be examined. In this study, only males with Parkinson's and male carers discussed isolation or embarrassment in situations like, for example, holding an Arabic coffee cup or drinking and serving coffee. This indicates that being unable to fulfil the social role of a host or guest in an acceptable cultural manner (e.g. by drinking traditional Arabic coffee) leads to isolation. Interestingly, Gultekin, Ozdilek and Bestepe's (2014) study of Turkey, an Islamic country in the Middle East that shares many similarities with Saudi Arabia, found that males with Parkinson's exhibit social phobia, an anxiety disorder involving excessive fear of social situations, more than females with Parkinson's. The authors attributed this difference to the social roles of males in Turkish society (Gultekin *et al.*, 2014). It is important to note that, in Saudi Arabia, males have a more dominant social role within the family and the community than females.

The above discussion provides insights into the Saudi culture and the roles of men and women. It is important to note that, in cases of Parkinson's and accompanying life style changes, including changes in eating and drinking, Saudi gender roles might be reversed. In extreme situations, females might become the heads of house. Such a role shift was exemplified by one male person with Parkinson's, who said, '*I don't know... ask my daughter*', suggesting that his daughter was in charge with respect to Parkinson's and/or knowledge about the health and wellness of the family.

In summary, this study shows the direct impact of eating and drinking changes among people with Parkinson's on their carers. These findings may help SLTs and rehabilitation teams better understand how carers can engage in specific tasks to help their family members with Parkinson's. Though this study has primarily examined how people with Parkinson's perceive their eating and drinking changes, it has also revealed several other important findings regarding how Saudi culture influences the ways in which people deal with the changes and symptoms of their disease. In particular, this study has shown that issues like gender segregation, tribal life, the roles of females and males within Saudi culture and perceptions of Western medical and rehabilitation services are all connected and all influence how patients and their families understand, experience and cope with Parkinson's.

5.6. The role of religion

Islam permeates every aspect of Saudi life. *Wahhabism*, the education system and the type of Islam that most Saudis practice, guides all portions of a person's day. Therefore, it is not unexpected to find that Islam influences both the perceptions of the eating and drinking changes experienced by people with Parkinson's and the impact of these changes on all involved. The following passage from the Quran demonstrates the pervasiveness of the religion in all aspects of life:

Those who remember Allah while standing, sitting, and lying on their sides, and meditate on the creation of the heavens and the earth. Then cry out: 'Our Rabb! You have not created this in vain. Glory to You! Save us from the punishment of Fire. (Quran, Al-i'Imran 191)

The findings of this study indicate that people with Parkinson's and their families have strong Islamic beliefs that influence the ways in which they cope and deal with Parkinson's and its related eating and drinking changes. The effect of Islam was prominent throughout the interviews with both people with Parkinson's and their carers. The interviewees' religious beliefs influenced their willingness to discuss their symptoms and changes, the ways in which they dealt with changes and the ways in which they sought help and intervention.

The current study agrees with Yamey and Greenwood's (2004) study, in which, when faced with illness, Muslims believe that they are being tested and that they must maintain their faith in Allah. Specifically, the present study suggests that many seek conventional medical help as part of their religious beliefs about cures, but that rehabilitation without medicine or a cure may be interpreted differently in Saudi culture. This challenge was illustrated in the focus group, in which the SLTs expressed their frustration at the very low compliance and attendance of their patients. For example, one SLT described the importance of *albir* and its relationship to rehabilitation compliance. S, a SLT participant in the focus group, gave an example of a daughter who could not adhere to the SLT's instructions because she felt that they conflicted with her Islamic upbringing. In this example, which dealt with a patient with a voice problem, the daughter could not follow the SLT's instructions to wait until her mother raised her voice to answer because she felt that she must answer her mother right away. In the daughter's mind, the recommended rehabilitation action conflicted with her beliefs about her

role as a daughter in Muslim culture. On the other hand, Amal, a carer, gave an example of how she used the religious concept *Ibtala* in a positive way to help counsel her mother and remind her that she was specifically chosen by Allah for this test. The daughter also suggested that her mother was not the only one undergoing the test; instead, the whole family was being tested, and she prayed for all of them. These two examples show how religious beliefs can have a positive or negative effect on the ways in which Parkinson's patients cope with the symptoms or management of the illness. In sum, these findings suggest that repeated rehabilitation efforts may conflict with patients' religious beliefs; however, further study is required to explore this multifaceted issue

The interviews with the people with Parkinson's showed that their Islamic beliefs were a factor in their ability to seek help, preventing them from learning about the disease. However, based on the interviews with the carers, it was clear that these beliefs were experienced as positive by the people holding them. People with Parkinson's thought of Parkinson's as one of many expected tests from Allah, since these kinds of tests (*Ibtala*) are part of Muslim life. Islam also influenced the role of the carer. The following passage from the Quran describes the foundation of this belief:

For thy Sustainer has ordained that you shall worship none but Him. And do good unto [thy] parents. Should one of them, or both, attain to old age in thy care, never say 'Ugh' to them or scold them, but [always] speak unto them with reverent speech. (Quran, Al-Israa 23)

This passage is one of the most commonly recited passages of the Quran. In school, Saudis are repeatedly taught the importance of caring for their parents and how Allah has linked his worship with obeying and caring for elders. Although informal carers can be wives, husbands, daughters, sons or other relatives or friends (Glenn, 2007), in the current study, it is significant that daughters represented the largest group of carers and that there were no husband carers. This finding is similar to that of Yamey and Greenwood (2004), who also addressed the importance of carers and stated that, in Islam, during times of crisis, there is a strong duty to help parents in their rehabilitation process. The interviews in the present study supported Yamey and Greenwood's (2004) results, showing that carers encouraged their parents to attend SLT sessions, sometimes to the point of prioritising their parents' health over their parents' comfort or wishes.

Ibtıla, as a concept and as a term by itself, appeared many times in the interviews with people with Parkinson's and their carers. It was influential not only as an underlying theme that played a role in how eating changes affected the lives of people with Parkinson's and their carers, but also as a barrier to conducting in-depth interviews. Once we discussed the changes that people experience, how these changes affect their lives, their belief in *Ibtıla* and how Parkinson's is a test that good Muslims should endure and accept, the interviewees became reluctant to discuss Parkinson's and its changes, seeing the act of discussing as an act of complaining. Since most of the interviewees were unfamiliar with the concept of talking about the disease, whether for research purposes or in support groups, they were unable to separate 'discussing' from 'complaining'. Their strong belief in *Ibtıla* made it harder for them to discuss Parkinson's openly. Mohammed, an individual with Parkinson's, when asked about what he would do about the changes to his eating and drinking, said: '*What do I do? Nothing . . . I do what I can . . . I am patient, and I leave it to Allah*'. Rashid, the son of a woman with Parkinson's (Fayza), was more explicit: '*This is an Ibtıla from Allah, and we are believers . . . Alhamdulillah . . . Allah will make things better*'. Rashid used the term *Ibtıla* in conjunction with identifying himself and his family as believers, stating that *Ibtıla* is a test that they had accepted. He also made his confidence explicit, stating that Allah would eventually relieve him and his family and that their hardship was temporary.

The findings of this study also suggest a need for caution when interpreting the religious phrases that appeared in the interviews. Although the interviewees exhibited strong Islamic beliefs, it was difficult to differentiate between expressions of belief and linguistically common phrases used to indicate something else. The commonality of Islamic phrases in Saudis' conversations suggests that, at times, they might lose strength of meaning. For example, *Inshallah* means, 'If Allah is willing...', and it must be used with such phrases as, 'Tomorrow I will do so and so'. However, the excessive use of this phrase might lessen its meaning to no more than a 'carrier phrase', which SLTs described as phrases that extend the length of a sentence. The following excerpt from the Quran explains the pervasiveness of these phrases in common speech:

And never say of anything, 'I will do that tomorrow'. Except [when adding], 'If Allah is willing. (Quran, Al-Kahf 23)

This example highlights the difficulties involved in interpreting some of the quotes and conversations from the interviews. As was discussed in the findings chapter, the participants

of this study used many religious phrases, and the researcher, who belongs to the same culture, sometimes took these for granted. It was only during the analysis stage that the researcher felt a need to point to these phrases and to pay attention to when and where they were used. For example, Manal, the daughter of a man with Parkinson's (Abdulaziz), was asked about the changes that she perceived her father to be experiencing. She replied using three Islamic phrases typically used when people are in mourning or have heard sad news: *'Alhamdulillah, to Allah we belong and to Him is our return, there is no strength nor power except Allah'*. This answer indicated that the carer saw Parkinson's as a test and that she felt a need to declare her faith in Allah and His action and strength before she could feel comfortable discussing her father's symptoms.

In sum, the Islamic religion was a strongly influential factor in understanding the attributions and behaviours of people with Parkinson's and their families in this study. This finding suggests a need for future studies to consider beliefs about health, wellness and locus of control when studying issues of health care.

5.7 Implications for clinical practice

Reports indicate that there is a common failure in translating research results into clinical practice (Marteau *et al.*, 2006). The findings of this study will be reviewed in this section to examine their implications for clinical practice. This section will discuss the following themes: restrictions related to the consumption of thin liquids, the issue of thickened or modified food, the impact that modified food and fluids has on quality of life, issues associated with managing illness, and the relationship between the participants and healthcare workers as well as the pertinence of the HBM and COM-B models.

Restricting patients from consuming thin liquids (e.g. water, coffee, and tea) is a common and frequent recommendation by SLTs when they suspect aspiration or penetration. This restriction is typically considered one of the first and safest recommendations for people with Parkinson's. When SLTs note any signs of aspiration in the VFS, they usually recommend that the patient refrain from drinking the types of liquids that were aspirated. Thin liquids are usually the most problematic and, thus, are the most frequently restricted. However, this study revealed the difficulties that people with Parkinson's have in adhering to these restrictions. Specifically, though these recommendations are designed to secure the patients' safety, they restrict people with Parkinson's from participating in events with family and guests and from

enjoying the same drinks or food. In sum, restrictions on thin liquids make it hard for people with Parkinson's to have normal social lives.

The issue of thickened or modified food was not directly discussed in the interviews. However, it was raised when participants discussed difficulties they faced when they could not eat or drink specific things because of their SLTs' recommendations. The carers also mentioned challenges related to cooking and preparing different food for people with Parkinson's and the rest of the family. Some individuals with Parkinson's specifically indicated that their reason for not wanting to socialise or receive guests was their inability to drink coffee with them.

Few studies have investigated the effects of this treatment on general quality of life. A systemic review to examine the impact on quality of life based on modifications to food and fluids showed that this type of treatment is associated with a poorer quality of life (Swan *et al.*, 2015). SLTs need to be aware of issue and explore multiple ways to support treatment. In a 2005 study in the US on SLTs' practice of using thickened liquids, half of the SLTs indicated that they 'rarely' or 'never' considered cultural factors when prescribing thickened or modified food (Garcia *et al.*, 2005). Very few SLTs indicated that their patients liked the thickened consistencies, while 61% noted that their patients' initial attitudes toward thickened consistencies either did not change or worsened.

This finding suggests that this treatment strategy might not be culturally sensitive, given the differences between the recommended diet and the traditional Saudi diet. To address this issue, SLTs should consider cultural factors when working with people with Parkinson's to develop new and feasible ways to reduce the risk of aspiration without restricting foods or liquids. For example, the latest research on oral hygiene has shown promising effects related to limiting aspiration pneumonia without the need to restrict the patient from specific liquids (Sjögren *et al.*, 2008; Sørensen *et al.*, 2013; van der Maarel-Wierink *et al.*, 2013). SLTs might need to consider working with people with Parkinson's and their carers to improve oral hygiene instead of restricting them from specific liquids.

With regard to feelings of being in control of their illness, this study's findings suggest a need for further consideration of cultural issues that affect beliefs about who has power over illness. Participants in the current study attributed their illness and coping to the external source of Allah, the responsibility for their treatment to their carers (typically daughters), and their illnesses as something which they could not change, since it is normal for people to

experience changes as they age. The inability of SLTs to provide treatments that patients considered satisfactory requires further investigation.

Several studies have shown that HBM-based educational intervention programmes are successful in improving patients' knowledge and behaviours in other health issue contexts (DiMatteo *et al.*, 2007; Daleboudt *et al.*, 2011; Iranagh *et al.*, 2016). In a review of the literature on the relationship between patients' adherence and disease severity, DiMatteo *et al.* (2007) found a correlation between patients' beliefs in the threat and severity of a disease and their adherence to treatment. In more severe conditions, worse adherence was associated with poorer health. In many studies, HBM dimensions include general health motivation and perceived severity and costs, which have been found to be uniquely associated with appointment-keeping for treatment of a chronic disease (Daleboudt *et al.*, 2011). Consequently, it is recommended to further explore this model in relation to Parkinson's patients in Saudi Arabia.

A recent study that asked women with Parkinson's to describe the meaning of 'feeling well' found that the women felt well when they could direct their own lives, even when their bodies were experiencing illness and disturbance (Olsson and Nilsson, 2015). Specifically, women with Parkinson's reported feeling well when their illness was not the dominant experience of their daily lives. They also said that feeling needed by others helped them feel well. This suggests that Parkinson's treatments should consider patients' everyday life experiences that are taken over by the illness or changes in eating and drinking, which the current study shows are important and pervasive. Specifically, the findings of the present study suggest that treatment should focus on minimising patients' dependence on carers. To address these issues, treatment programmes could include techniques that may aid in social eating situations, such as timing medications to be taken before meals or encouraging patients to bring their own food or take a larger cup to use for coffee when visiting others. Such actions might help people with Parkinson's become more engaged in SLT sessions by giving them back some of their independence and agency and allowing them to participate in daily social life.

Another consideration regarding the treatment of Parkinson's is the stigma of Parkinson's from a Saudi perspective. The findings of this study highlight the importance of perceptions related to having someone in the family with Parkinson's. For example, one wife stated, '*We will be gum in people's mouths*', describing how she did not want her maid to know about her husband's Parkinson's so other people would not find out about his condition. This situation has implications for how social support for people with Parkinson's and their families should

be approached and addressed within Saudi culture. Group support is needed, but it cannot be “imported” from other countries and needs to be designed with Saudi culture in mind.

Further, the findings suggest a complex relationship between the participants and their healthcare workers. The SLT focus group showed that patients seemed disappointed with their initial visits with SLTs and tended not to return for subsequent visits. These findings suggest a need to explore factors that influence patients’ compliance with the treatment advice of healthcare workers and how these factors are important to improving quality of life and reducing symptoms among people with Parkinson’s (Murray, 2014; Ogden, 2014). Additional exploration of health beliefs and their psychosocial impacts on patients and families when considering the most appropriate and effective treatment options is needed.

This study has shown that patients, their families, relatives, culture, religion, as well as rehabilitation services and country health policies, are all involved in how patients experience, cope with, and manage eating and drinking changes secondary to Parkinson’s. Michie et al., in their book, ‘ABC of Behaviour Change Theories’, indicated the complexity in addressing behavioural changes. They point out that there are interrelated components of the targeted behaviour, and it is almost impossible to identify a “key ingredient” (Michie *et al.*, 2014, p. 25).

As a first step, SLTs need to determine the broad approach they want to adopt before taking the steps required for intervention design. The Saudi SLTs’ awareness of the findings of this study will provide the basic steps needed to design behavioural change interventions. The results of this study, along with the COM-B model, provide the first steps.

SLTs should identify the target behaviour. Based on the COM-B model, the behaviours mentioned in the focus group cannot be grouped as target behaviour even if the SLT sees it this way. The SLTs mentioned that PwP do not adhere to their advice and recommendations and do not attend the sessions regularly. However, following the COM-B model, these two behaviours have different components (conditions); therefore, the interaction of these components will be different from one behaviour to another. SLTs should be urged to use the COM-B model as the framework for developing culturally sensitive interventions.

As previously explained, the COM-B model views behaviours as a part of a system where the conditions (capability, opportunity, and motivation) interact to produce or elicit a chosen behaviour. The people with Parkinson’s in this study showed that they indeed lack the needed knowledge about their conditions, changes that come with this condition, as well as the

benefits of rehabilitation (and the repercussions of not following the SLT's advice); is in COM-B terms, this indicates lack of capability. This study also showed that they lack in opportunity, which comprise the external factors that affect behaviour. In this case, the limited number of SLT clinics in the country and the transportation issues that come with gender roles in Saudi Arabia are also opportunity barriers for the desired behaviour.

The third condition is motivation, which includes reflective and automatic mechanisms. The reflective mechanism involves the beliefs that the person has, in this case, participants' religious beliefs and their cultural beliefs about disorders, poor health, and cure. Also involved are their beliefs about *Ibtala* and how this belief conflicts with complaining and discussing their conditions with medical professionals. Motivation also involves the person's response and desires, and the focus group showed how the PwP responded to the SLT services and the low participation after the first session. This indicates that we need to identify what is happening in the first session to elicit such a response.

COM-B, as was explained, is a system where all the conditions are linked and influence each other, and the interaction between the conditions produces the behaviour. In this case, the SLTs need not only identify these conditions but also consider how they can impact one another to produce the behaviour needed. It is obvious from the findings of this study that motivation has an impact on capability and the strong Islamic beliefs (including *Ibtala*) that these participants have would affect their ability to understand their condition and appreciate the different types of management for changes that come with Parkinson's. One method Saudi SLTs can look into is raising knowledge and awareness of Parkinson's in PwP as well as their families (both close and extended) by eliciting the services of mosques' Imams. In this way, seeking help and working toward improving the condition is not viewed as something that contradict their *Ibtala's* beliefs. Using mosques to establish support services for PwP and their families might be a vital step in breaking the religious and cultural barriers that are playing a role in preventing PwP from seeking help. Linking Islam and its values with seeking medical and rehabilitation services is the key that would break the barrier and improve adherence to health services. Mosques can be excellent community centres for support groups of people with Parkinson's and their families.

Along with that, local SLT services need to work with health policy-makers to make SLT services more acceptable and less difficult to obtain. Establishing SLT services in rural areas and providing hospital transportation services (addressing the lack of opportunity in the

COM-B model) will make SLT services more accessible and reduce the People with Parkinson's urge to cancel or not show up.

5.8 Limitations and implications for future research

There were several limitations to the data collection process, including location, cultural challenges, the match between the characteristics of the researcher and the participants and linguistic translation challenges. It is well known that the time and place of interviews, as well as the status and gender of the interviewer, can have a significant influence on the content and structure of interviews in qualitative research, irrespective of the culture in which they are conducted. In this study, it became apparent that significant factors related to the place of the interviews and the status of the interviewer might have influenced the process and outcomes of the interviews.

The following discussion considers two notable issues: the gender of the interviewer (given Saudi Arabia's laws concerning sex segregation), and the location of the interviews. The interview locations were selected to address anticipated problems related to interviewing the participants in their homes. However, the selected locations of the interviews may have had implications beyond convenience of travel. The following paragraphs reflect on how the research could have produced different results if the interviews were conducted in the participants' homes.

Conducting the interviews inside the participants' homes may have provided greater access to information about the female participants, since the interviews could have been less formal. However, as a guest sitting in a formal area of the house, it would have been difficult for the researcher to interview the participants alone, and interviewing the male participants might have been inappropriate (given the researcher's gender). The decision to not interview the participants in their homes was made to address these anticipated cultural challenges of being a female researcher and a Muslim Saudi woman. However, this decision may have created a different kind of barrier, since greater insights into the lives of people with Parkinson's and their carers might have been achieved through home visitations. Such an approach would have needed to be carefully planned. Future studies conducted in participants' homes might consider matching the gender of the interviewer with that of the interviewee so that the interviewer can conduct the interview in the same section of the house as the interviewee. Alternatively, the interviewer could allow the interviewee to choose the time of the interview

(or to refuse specific times), thereby avoiding mealtimes and limiting the interviews to short periods. This might also reduce the time required to dedicate to the pleasantries customary of Saudi receptions of guests.

Interviewing people with communication disorders is a challenge in itself. In this study, the communication problems of the people with Parkinson's, which included short answers, monotone descriptions, voice problems and limited facial expressions, all made it difficult for the interviewer to obtain information or detect cues to help in probing and asking for details. The carers' interviews, by contrast, were richer in information, offered a larger body of text data, and did not require as many prompts for explanations or examples. Thus, the carers' interviews were used to support some of the limited interviews of the people with Parkinson's. This approach could be a limitation of the study, since, while the researcher was able to explore the impact of the changes in eating and drinking on the families, she was less successful in exploring their impacts on the people with Parkinson's. The speech difficulties of the people with Parkinson's may have prevented a deeper exploration into the effects of their eating and drinking changes; however, since the researcher was a SLT with experience working with people with Parkinson's, this might not have had a noticeable effect on the results, since the researcher has been trained to understand people with Parkinson's speech, as well as to know where to sit and when to give cues for them to raise their voices.

Another point worth discussing is the carers' reluctance to describe their burden of care. The researcher felt reluctance on the part of the carers to address the burden of care, which resulted in both shorter answers and extensive prompting from the interviewer. The carers also increased their use of religious phrases when they were answering questions relating to the impact of Parkinson's or changes in eating and drinking on their own lives. These observations suggest that the carers were not comfortable describing or discussing the impact of Parkinson's on themselves. This has implications for the cultural appropriateness of the use of the types of measures that are typically used to study carers. The literature focusing on carers' burdens uses such measurements such as the Zarit Burden Inventory (Zarit *et al.*, 1986) and the Caregiver Distress Scale, which ask carers to score their stress/distress (e.g. 0 = no stress and 10 = overwhelming stress). These scales are difficult to apply in a Saudi context because carers' culture and religious upbringing state that it is 'not Islamic' to complain about caring for their parents. Future research tools should be designed or modified to better measure carers' burdens, with careful consideration to avoid feelings of guilt and,

subsequently, invalid scores. This concern also needs to be considered from the viewpoint of *Ibtla* for both people with Parkinson's and their carers.

Translation is another important issue affecting the process of conducting research in Saudi Arabia. Translating the transcripts was very difficult, since the phrases were purely Saudi Arabian and it was often difficult to find an equivalent meaning in English. The sample included participants from all five of the main regions of the country. There were many dialects and accents from various Saudi sub-cultures, making it very difficult to fully understand or translate the interviews. Other sources were sought to explain certain wordings. For example, people who had experience with multiple dialects (and who were not part of the study) were asked to clarify certain meanings. These issues were only prominent in interviews with the people with Parkinson's and did not affect the carers' interviews. This potential limitation has implications for future research with older Saudis, due to the diversity of dialects within the country. However, it may be less of an issue for participants from younger generations. Saudi Arabia is becoming more multicultural, and young people use a more unified dialect that can be comprehensively labelled 'the Saudi dialect'. Additionally, translation issues may be less relevant in future studies, given the rise in familiarity with the English language among younger generations of Saudis.

A major challenge in this study was the lack of follow-up interviews to clarify questions that arose during the analysis. This was mostly a function of the geographic location of the participants in relation to the researcher, since the researcher had returned to the UK to perform the analysis. Remote communication with the study population was a challenge because of the participants' limited access to technology and their lack of comfort sharing information via more modern technological means (e.g. email). Telephone interviews were also not feasible due to the communication difficulties of people with Parkinson's and the marked differences between phone interviews and face-to-face meetings. In particular, prior research has documented the need for face-to-face interviews to collect patient and carer feedback and reflections on their experiences of illness to inform improvements in health research (Janssen and MacLeod, 2010). In sum, given these limitations in communication between the researcher and the participants, it was deemed too great a challenge to conduct follow-up interviews.

The interviewees shared their views on how they experienced their world in relation to swallowing and Parkinson's. Since the participants shared the same culture, their views can be taken to represent the cumulative and valid perspective of people in similar situations in Saudi

Arabia. We can speculate that these views represent of how Saudi culture views the experiences of changes in eating and drinking caused by Parkinson's. However, caution is needed when interpreting and assigning weight to the participants' responses. As Silverman (2013, p. 45) questioned, 'How far is it appropriate to think that people attach a single meaning to their experience?' Initially, when designing the study, the researcher had planned to use the participants' interview responses to access their experiences, with the understanding that it might not be possible to capture the full experience. Therefore, while it must be noted that these views do not represent the entire range of views that could be found in Saudi Arabia, this thesis is certainly important in that it provides a sample of views that offer valuable information and can serve as a basis for and encourage further research.

It is important to investigate cultural influences when conducting research in Saudi Arabia or in countries that have a similar cultural background (Arabic and Islamic). This study adds to the general literature describing the Saudi culture. This body of literature shows that the family dynamic is ruled by the culture to which a family belongs (Metz and Library of Congress. Federal Research, 1993; Dickson, 2015). Saudi families tend to be large, and daughters and sons typically live in the same house as their parents until they get married. This large family dynamic, combined with the Saudi interpretation of Islam and tribal rules, affects how these families deal with the changes caused by chronic neurological conditions. Although this study aimed to interview the carers of people with Parkinson's, it also unintentionally included individuals who considered themselves primary carers but who were actually family members living with people with Parkinson's and not providing care. This is an important dynamic that should be taken into consideration in future research on health issues in Saudi Arabia.

This study also revealed Saudi-specific issues concerning the relationship between the interviewees and the researcher. First, though the literature on qualitative interviews explains the ethics and guidelines for conducting research interviews, including the need for the researcher to maintain a certain distance from the interviewee and to identify himself as a researcher (Gillham, 2005), following these guidelines proved difficult in the Saudi context. During the first set of interviews, the researcher struggled to communicate with and interview people with Parkinson's. She attributed this struggle to her inexperience, the communication challenges faced by people with Parkinson's and their inability to relate to a research interview. However, during the later interviews, it became clear that the researcher needed to take on a social role in order to obtain more details from the participants. While the researcher identified herself as a researcher and explained in detail what that meant, in later interviews,

she also added the title '*um-Saad*' (the mother of Saad). This title facilitated communication with the people with Parkinson's, since, without any title to use, they assigned the researcher the title of 'Dr.' (since titles such as Miss and Mister are not used in Saudi Arabia), due to the cultural norm of not calling strangers or acquaintances by their first names. The use of the title *Um-Saad* also gave the interviewees a socially accepted name that differentiated the researcher from the medical team and encouraged the interviewees to ask the researcher personal questions, such as whether she was from Saudi Arabia and what her family was like. These brief interactions, in turn, encouraged the people with Parkinson's to open up and give more detailed answers during the interviews.

Second, as Maxwell (2012) indicated, a researcher should not separate her life from the research, since this could limit a major source of insight and validity. The researcher's role as a Muslim Saudi woman may have both helped and hindered the data collection process; however, it certainly provided unique insight into the behaviours and responses of the participants. For example, male interviewees, once comfortable with the interview atmosphere, began to make eye contact and talk normally. However, in the middle of the interview, they typically looked at the wall in front of them or at their feet and legs. This behaviour could stem from Islamic culture, which requires men to avoid looking at women directly by lowering their eyes. While some of the participants remembered to do this during the interviews, others tended to forget once they became involved in the interview. This behaviour, which might reflect the participants' lack of comfort talking to an unfamiliar woman, is an issue that researchers should consider when planning qualitative research: Gender relations may affect the comfort level of the participants, which may affect data collection. One possible solution could be using a male interviewer when interviewing males, which could increase their comfort levels and, thus, yield more information.

In addition to challenges related to gender, the research approval process also presented unique challenges in Saudi Arabia. Although ethical approval was granted by the ethical review board of Newcastle University early in the research process, the process for gaining ethical approval took longer in Saudi Arabia, delaying the recruitment phase. In both institutes, some members of the health team were willing to begin the recruitment process before receiving approval; these individuals saw the approval not as an important step, but as a technicality that could be delayed or completed later. Regardless, if the ethical approval

process in Saudi Arabia had been quicker, more time could have been dedicated to recruitment.

Finally, the results of this study suggest two major considerations for future research. First, they emphasise the need for caution when interpreting the findings of other studies on swallowing. Many existing studies on swallowing have combined enquiries about swallowing with questions about speech disorders or communication disorders, which is understandable because all these disorders are investigated and managed by the same professionals: SLTs. By contrast, scarce research has paired swallowing changes with changes in eating and drinking, therefore overlooking the role of this function as an ADL or social concept. An example of a study that overlooked this issue was that of Hammarlund *et al.* (2012), who attempted to build a concept map of prioritised areas for people with Parkinson's when measuring outcomes. They paired swallowing with speech disorders and used different items to measure quality of life, self-efficiency, socialisation and participation in society (Hammarlund *et al.*, 2012). Based on the findings of the current study, it is possible that, if the Hammarlund *et al.*'s (2012) study had considered eating and drinking changes as separate items, the outcomes for quality of life may have been different. Second, the findings suggest that accessing medical and rehabilitation services are a major issue. Although some of the participants complained of severe issues with motor and other symptoms indicative of Parkinson's, as well as issues with eating and drinking, several reported not being referred to a SLT; instead, these individuals had worked with neurologists. Many acted as if they had been recently diagnosed with Parkinson's, even when they had been aware of their diagnosis for years. For example, Saad had been diagnosed with Parkinson's for three years and was already in a late stage of Parkinson's, according to assessments. He and his son both expressed that his motor symptoms and swallowing symptoms were affecting their lives. However, for the three years of his illness, Saad had only been seen by a neurologist and had never been referred to any SLT services for his communication or swallowing issues. To extend our understanding of situations like this one, further studies should explore the course of treatment in Saudi Arabia to determine the differences and similarities between this course of treatment and those followed in other countries.

5.9 Discussion Summary

In summary, the impact of physiological changes on the lives of people with Parkinson's and their carers and families is rather complex. This chapter has attempted to describe this complex relationship and found that social and cultural norms in Saudi Arabia present a unique challenge for both patients and carers. This challenge is largely due to issues regarding gender relations and deeply embedded religious beliefs. Ultimately, this has major implications for clinical practice and highlights the importance of considering cultural and psychosocial issues when designing and implementing effective treatment plans. The information provided by the population sampled in this study clearly illustrates that those who fail to consider such issues are less likely to produce effective treatment plans.

5.10 Final reflection

This thesis represents a long and enlightening journey of four years and nine months. A crucial part of this journey has been my development and growth within my role as a qualitative researcher.

I started this journey with a clinician's mind set, which had a narrow view of the problem and the potential solution. I was looking for immediate and implementable solutions. My personal and professional motivations were the starting points of my work. Now, although I would not call myself an experienced researcher, I do have a better understanding and a much deeper appreciation of qualitative research.

Over the course of the past four years, both the study and my ability as a researcher to conduct the study have grown. Among other skills, I have learned to critically read an article, to address the challenges of data collection and analysis and to produce a final written synthesis of my work. Through the process of developing these abilities, I have discovered a great deal about myself and my strengths.

My identity as a SLT, a Saudi and a woman was the lens through which I viewed, reviewed and analysed the data. This interpretive lens was constructed from several different lenses, each of which represents my experiences and my knowledge of the culture and profession to which I belong. Additional lenses were provided by the skills that I developed as I progressed through the work of the research.

The literature that I read at the start (and throughout) this journey contributed to developing my knowledge of the extant work and challenges related to the topic of this thesis. This thesis pushed me to read scientific studies outside the body of literature with which I am familiar, exposing me to studies in the fields of sociology, psychology and other health-related fields. I also gained extensive knowledge of qualitative research and methodological approaches. Ultimately, these readings sharpened my critical eye and allowed me to not only accept and understand, but also question previous authors' methods and conclusions. This experience also challenged my own assumptions and beliefs about health services, expanding and reshaping my view on the role of culture in issues of health and illness.

Listening and reading to the accounts of the people with Parkinson's and their carers, as well as to the SLT focus group discussion, allowed me to view the challenges faced by all of these participants from a different perspective. I am now a researcher, not a SLT; through this lens, the comments and insights of my study participants helped me understand the views and challenges of people with Parkinson's and their carers with respect to eating and drinking. This experience changed me as a person, affecting my perceptions of myself, my profession and my culture.

In addition to my interactions with the study participants, my countless discussions with my supervisors also allowed me to view my profession and my culture differently. Working with and receiving feedback from the experienced academic researchers on my PhD supervisory team offered me numerous opportunities to learn and search for new and different ideas. The guidance of these individuals was invaluable during the fluctuations and challenges of this PhD journey, including periods of high and low productivity, difficult phases and conflicts with my family life. Overall, my PhD supervisory team helped me maintain my momentum, gave me direction and kept me on track towards submission. Their guidance throughout the research process also allowed me to acknowledge my success and achievement and to take ownership of this project.

In sum, following the experience of completing this thesis, I now have greater confidence in my abilities as a researcher. However, this journey has also showed me that there is a great deal of work to be done. I now know what direction I must pursue in the next few years.

5.11 Conclusion

This section summarises the conclusions drawn throughout the study, from the literature review to the data analysis.

The literature review showed that there is little research on how people with Parkinson's perceive changes to eating and drinking and a significant lack of research on the impact of these changes on people with Parkinson's, their carers and their families. The literature review also showed that Parkinson's research in Saudi Arabia is very scarce and that there is no research on how people with Parkinson's perceive their eating and drinking changes within this culture, despite the growing global attention to the impact of culture on how people cope with symptoms and changes in illness. Therefore, the contributions of this study are unique, as this is the first phenomenological study to consider the perceptions of people with Parkinson's regarding their eating and drinking changes in Saudi Arabia. This study offers novel insight into the impact of the Saudi culture and Saudi traditions and norms on the attitudes of Saudi people towards illness.

First, the study's findings have shown that people with Parkinson's lack knowledge of their diagnoses and illustrated how this lack of knowledge impacts not only the way in which people with Parkinson's perceive medical management, but also their willingness to participate in rehabilitation programmes.

Second, the interviews with people with Parkinson's has clearly shown the struggles and challenges faced by people with Parkinson's in general and, in particular, with respect to eating and drinking changes. The different dimensions of these challenges and how they affect the personal, social and family lives of people with Parkinson's have been revealed and explored. Furthermore, the findings have shown the perceptions of people with Parkinson's regarding these eating and drinking changes and the impacts of these changes on their identities; their personal, social and family lives; their family dynamics; and their relationships with their carers and relatives (both immediate and distant). Additionally, the burden of care, particularly with respect to how changes to eating and drinking add to and disturb the role of the carer, was also examined.

The findings of this study illustrate the important role that Islam plays in the lives of Saudi individuals. Several indicators, ranging from the participants' heavy use of Islamic phrases during their interviews to the ways in which people with Parkinson's and their carers accepted

and dealt with changes in eating and drinking, reveal the influence and power of religion (Islam) on people's perceptions, attitudes and behaviours in relation to illness.

The findings clearly show that issues with gender roles and gender segregation influence the ways in which people with Parkinson's and their carers manage their eating and drinking changes. The critical role of gender was evidenced by the carers' responses to and (in)ability to engage in certain behaviours with people of other genders with Parkinson's, particularly with respect to eating and drinking changes.

In sum, this study has highlighted the magnitude of the influence of culture on the ways in which people with Parkinson's cope with their eating and drinking changes. The study has shown that certain elements of culture can affect how people accept and participate in rehabilitation programmes, such as SLT services. The focus group data illustrates the challenges that SLTs face in implementing Western-based assessment and therapy procedures in Saudi populations while the interviews with the carers show the difficulties people with Parkinson's face in complying with SLT recommendations.

For SLT services to effectively serve people with Parkinson's in Saudi Arabia, health services need to be modified to be more culturally sensitive. In particular, tools need to be updated, and SLTs need to be engaged in educational programmes to help people with Parkinson's understand the impact of the disease and the changes it involves, as well as the need for rehabilitation. This research suggests that, in the goal-making process of SLT sessions, both patient and carer involvement are necessary

Although this study has illustrated the uniqueness of the Saudi culture and how this impacts the lives of people with Parkinson's and their families, the study also reveals similarities between some of the study findings and other studies with similar samples. The comparability of these disparate findings allows this study to contribute to the existing body of literature.

Overall, this thesis suggests that cultural traditions, social norms and individuals' own perceptions of society impact the ways in which we deal with health and illness. Specifically, it shows that Saudi culture plays a key role in the ways in which people with Parkinson's in Saudi Arabia view and deal with Parkinson's-related changes to their eating and drinking.

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Glossary

ADLs	Activities of daily living, which are routine activities that people tend to do every day without needing assistance
Allah	Arabic word for God
FEES	Fiberoptic Endoscopic Evaluation of Swallowing. A Procedure used by a SLT to evaluate swallowing. The SLT uses a very small tube with a camera and light on the end that is connected to a computer and video monitor.
Hadith	Sayings and actions of the prophet Mohammad
Holy Quran	Central religious text of Islam
ICF	International Classification of Functioning, Disability, and Health
KSA	Kingdom of Saudi Arabia
Movement disorders clinic	A specialized clinic in a hospital that deal with movement disorders but mainly Parkinson's
OT	Occupational Therapist
PD	Parkinson's
PwP	People with Parkinson's or Person with Parkinson's
Sharia law	Legal framework for Islam
SLT	Speech and Language Therapist
Swallowing clinic	Clinics that are part of the speech and Language therapy department which are designated for dealing with patients that were referred with concerns about their swallowing. they are run by speech and language therapists

VFS/	Videofluoroscopic swallowing study. A procedure used by SLT to assess
VFSS	a patient's swallowing. The patient swallows a variety of different liquids while the radiologist takes a number of video X-ray images
<i>Alshakwalalah</i>	Islamic phrase meaning we can only complain to Allah
<i>Astaghforallah</i>	An Islamic phrase used when a person is seeking forgiveness from Allah because he/she feel they did wrong
<i>Azaym</i>	A word used to describe all kinds of social gathering
<i>Bialah</i>	A small glass cup in which traditional tea is served
<i>Hosh</i>	Part of the house that is outdoor (back/front yard) and used for sitting
<i>Jaresh</i>	Saudi porridge
<i>Kabsa</i>	A traditional Saudi dish which is rice cooked with meat or chicken
<i>Majilis</i>	The area in a house for formal sitting
<i>Makalat/</i>	The dining room of the house
<i>Almakalat</i>	
<i>Marag</i>	Traditional Saudi soup
<i>Qadar</i>	Predestination, an Islamic concept of divine destiny
<i>Sahwa</i>	religious reform movement
<i>Shahada</i>	A statement of affirming the Islamic faith. People on their death beds or who think they are dying are expected to say it
<i>Shaikh</i>	leader/prince of a Arabic tribe
<i>Silat-ur-Rahim</i>	An Islamic concept which refers to maintaining good relationships with relatives
<i>Subhanalah</i>	An Islamic phrase meaning "Glory to God", usually used as a phrase of exclamation (Praising God)
<i>Tibsi</i>	Large, central plate that everyone eats directly from

Wallah An Arabic expression meaning By god I promise you

Yabashir The host make sure everybody is eating/served food

Appendices

Appendix A: Focus group topic guide

Focus Group Document

Moderator: Kholoud Alhussain

Date:

Time:

Location:

Welcome message

I would like to welcome you all to this focus group and thank every one of you for your willingness to share your knowledge and experience in helping me in my research.

As you notice this focus group will be audio-recorded but I need to assure you that all the information we will share today will be anonymous and confidential.

We will start by introducing each of us, your name and the place you work in. I will start; my name is Kholoud Alhussain and I am a PhD student at Newcastle University and I will be the moderator for this focus group.

Introduction

The aim of this focus group is to discuss all the issues that relate to dysphagia in people with Parkinson's. This focus group also aim to discuss the challenges the person with Parkinson's and their family face with dysphagia as well as the SLT management challenges.

We would like to find out your ideas and opinions as speech and language therapists about this topic. What you feel are the issues that are important to raise and that stand in the way of delivering the best or optimum services to your patients.

The questions:

- 1- To start with to describe the people with Parkinson's that come to the SLT clinic and complain from dysphagia.
- 2- What do you feel about the management that you provide to these patients?

- 3- If there is anything you would change in the management that you provide in relation to dysphagia, what is it?
- 4- Talk to me about your patient's participation in the therapy sessions/treatment programme you provided.
- 5- How do you feel about the benefit of these sessions on your patients?
 - Prompt: Compare to other patients
 - Prompt: compare to your expectations and readings
- 6- What areas do you feel need to be addressed when you do therapy for dysphagia in people with Parkinson's?
- 7- What challenges you observe on the carer side?
- 8- What can you talk about in relation to dysphagia impact on both people with Parkinson's and carer?
- 9- Is there anything you would like to add?

Closing:

Thank you all for participating in this focus group, I now would like to give each one of you a few moments to tell us if there is something you want to add or elaborate on any point that was mentioned that you want to emphasise or add.

Finally I would like to let you all know what we will do with the information we gathered today.

The conversation recorded today will be transcribed and then coded to extract the main points/themes that were raised. This will be reviewed by the supervisory team back in Newcastle University. This with the interviews I will conduct with the people with Parkinson's and their families will provide the results of this study which we hope will benefit the field of SLT in the country.

Thank you all for joining me.

Appendix B: People with Parkinson's Interview Schedule (Initial interviews)

Interview Schedule (Participant)

Introduction:

Hello, my name is Kholoud Alhussain. Thank you for agreeing to see me and talk to me. I want to let you know that although this interview is recorded, it will be anonymous and confidential. I would like to hear from you on issues effecting your eating. I will ask questions but feel free to talk about anything concerning your eating or your Parkinson's.

General Questions:

Tell me about yourself and your swallowing problem?

Prompt: how long have you had it? What happen during this time?

Comments:

Tell me 3 things that Parkinson affected your life?

Prompt: if swallowing among them, what is it? 1st, 2nd... if swallowing is not among them, should we say you're not bothered by your swallowing?

Comments:

Talk to me about your swallowing problem/difficulties/issues?

Prompt: describe your problem to me. What changed?

Comments:

How did your swallowing problem affect your life?

Prompt: where and how you eat? Problems you now encounter.

Comments:

Specific Questions	
Question	Comments:
<p>Tell me about the food you eat</p> <p>Prompt: food you like, Food you cannot eat</p>	
<p>Tell me about your mealtime?</p> <p>Prompt:</p> <p>Who eats with you?</p> <p>Where do you eat?</p> <p>Who else is there?</p> <p>What's the best part of it?</p> <p>What do you talk about during your meals?</p> <p>When do you feel you are tired the most?</p>	
<p>How long does your meal take from you?</p> <p>Prompt: each meal.</p>	
<p>How many meals do you eat? And when?</p> <p>Prompt: why do you skip ...Meal?</p>	
<p>Tell me about your family and eating with them?</p> <p>Prompts: How do you feel about eating with them?</p>	
<p>Do you need any help with your food?</p> <p>Prompt: who help you? When do you need the help? Describe the help you get</p>	

<p>What do you think about the services you received so far in relation to your swallowing problem?</p> <p>Prompts: what do like to see more of or less of?</p>	
<p>More Specific Questions:</p>	
<p>What do you want from a swallowing therapy program?</p> <p>Prompt: what do you think you will achieve?</p>	
<p>What are your expectations of a swallowing therapy program?</p> <p>Prompt: what is it that you want to see change in the way you swallow/eat?</p>	
<p>How is your swallowing therapy programme? Talk to me about it</p> <p>Prompts: how many sessions have you had? What do you do? What does the therapist do?</p>	
<p>How would you judge if a swallowing program is successful? And why?</p> <p>Prompts: how can it be improved?</p>	

Appendix C: People with Parkinson's Interview Schedule (Final interviews)

Interview Schedule (Participant)

Introduction checklist:

- My name
- Topic of the research reminder
- Audio-recorder reminder
- Confidentiality reminder
- The interview process
- You can ask questions

Topics:

Why are you here today? (Neurology clinic/SLT clinic)

What do you complain from?

Can you tell me about any problems you have with eating or with drinking?

Can you talk to me about your meals with your family?

Describe your regular meal?

Who do you like to eat with and why?

Do you need help with your food? Can you talk to me about that?

What are the challenges you face during eating?

What is (carer name) do when you eat your meal?

What else does she/he do?

What about other people? Who eat with you? Who do you like to eat with?

Have you sought treatment form the SLT clinic? Why? How?

Tell me about your experience with the SLT clinic?

What did the SLT tell about what you can/can't eat or drink? Why?

Can you tell me about the difference you noticed in your life in the last (years of PD diagnosis)? Describe these changes?

How did these changes affected you?

Talk to me about (name of carer)

What things does she/he do around the house?

How is her/his life now since (diagnosis)?

Conclusion checklist:

Is there something that we discussed and you feel you want to talk more about it?

Is there something you want to add?

What will I do with this interview information?

Do you have any questions?

Thank you

Appendix D: Carer Interview Schedule (Initial interviews)

Interview Schedule (Carer)

Site:

Participant Code:

Introduction:

Hello, my name is Kholoud Alhussain. Thank you for agreeing to see me and talk to me. I want to let you know that although this interview is recorded, it will be anonymous and confidential. I would like to hear from you on issues effecting _____swallowing. I will ask questions, but feel free to talk about anything concerning Parkinson's disorder of _____ or his/her eating and the effect it has on you and your care for him/her.

General Questions:

How much care do you provide for _____? And in what areas?

Prompt: is feeding one of them?

Comments:

Describe the swallowing problem _____ has.

Prompt: how long has he/she had it?

Comments:

Talk to me about your part in _____ eating and drinking?

<p>Prompt: how much involved are you? Where does your involvement start or stop?</p>	
<p>Comments:</p>	
<p>How did _____swallowing/eating problem affect your life?</p> <p>Prompt: time you spend, things you are missing.</p>	
<p>Comments:</p>	

Specific Questions	
Question	Comments:
<p>Tell me about the food (.....) eat</p> <p>Prompt: food he/she like, Food he/she cannot eat. Food he/she eat because of _____ eating restrictions.</p>	
<p>Talk to me about your mealtime</p> <p>Prompt:</p> <p>Who eats with _____?</p> <p>Where do you eat?</p> <p>What's the best part of it?</p>	

<p>What do you talk about during your meals?</p> <p>What changes you noticed recently in your meal?</p>	
<p>Do you eat with _____ or _____ eat alone? And why?</p> <p>Prompt: who eat first?</p>	
<p>How can you describe the mealtime?</p> <p>Is the mealtime a stressful or enjoyable time? Why?</p> <p>Prompt: what part of it is more stressful?</p>	
<p>How many times a week do you eat out? And where do you like to eat? Why?</p> <p>Prompts: is this your favourite place?</p>	
<p>More Specific Questions:</p>	
<p>As a person taking care of _____ what would you like to get from a swallowing programme?</p> <p>Prompt: what do you think he/she will achieve? How can the programme improve the mealtime?</p>	
<p>What are your expectations of (SLT name)?</p> <p>Prompt: what is it that you want to see change in the way _____ swallow/eat?</p>	
<p>How would you judge if a swallowing program is successful? And why?</p>	

Prompts: what do you want to see change or improve?	
---	--

Appendix E: Carers Interview Schedule (Final interviews)

Interview Schedule (Carer)

Introduction checklist:

- My name
- Topic of the research reminder
- Audio-recorder reminder
- Confidentiality reminder
- The interview process
- You can ask questions
- You are the carer of (Name of person with Parkinson's)

Topics:

Please talk to me about the challenges _____ face when eating and drinking?

What more can you tell me about _____ eating and drinking?

Describe a typical meal you have with____? Who eat with you? Where? What happen?

Do _____need help with his/her food? How? What do you (or others) do?

Are these changes to eating and drinking recent? Can you describe the changes to _____eating and drinking when you compare him to (time before PD?)

What is the impact of these changes on _____?

How can you see the changes in_____life after PD? And after eating and drinking changes that you just describe?

Can you tell me why do you identify yourself as the carer of _____?

Prompts: what is it you do that others don't do? What about during mealtime? Can you tell me about other family members' role during mealtimes?

What impact has these eating and drinking changes had on you?

What additional tasks are you now doing? What about other family members what do they do?

Have you sought treatment from the SLT clinic? Why? How?

Tell me about your experience with the SLT clinic?

What did the SLT tell about what you can/can't eat or drink? Why?

What impact has these recommendations have on _____? On yourself?

What more can you tell me about your life with your _____PD? And the changes that happened because of PD?

Conclusion checklist:

Is there something that we discussed and you feel you want to talk more about it?

Is there something you want to add?

What will I do with this interview information?

Do you have any questions?

Thank you

Appendix F: Data Form

Code		
Location of interview		
Medical Record number (MRN)		
Date of Interview		
Gender		
Date of birth	(from Medical file) (from interview)	
Age		
Living in (city/province)		
Living with	Person(s):	Number of people:
Carer name		
Carer relationship		
Patient awareness of Parkinson's		
H&Y stage	(from Medical file) (by PI)	
Diagnosis date	(from Medical file) (from interview)	
<ul style="list-style-type: none"> • Years since diagnosis 		
Medications		
Referral to Rehabilitation		
Referral to Rehabilitation		

Domestic help		
<ul style="list-style-type: none">• Nationality		
<ul style="list-style-type: none">• Role in care		
Interview length		
Comments		

Appendix G: Ethic approval Newcastle University



04 July 2014

Kholoud Alhussain

Institute of Health and Society

Faculty of Medical Sciences

Newcastle University
The Medical School
Framlington Place
Newcastle upon Tyne
NE2 4HH United Kingdom

FACULTY OF MEDICAL SCIENCES: ETHICS COMMITTEE

Dear Kholoud,

Title: Swallowing changes in people with Parkinson's in Saudi Arabia: Perceptions and practices.

Application No: 00766/2014

Start date to end date: 01 May 2014 to 1 February 2016

On behalf of the Faculty of Medical Sciences Ethics Committee, I am writing to confirm that the ethical aspects of your proposal have been considered and your study has been given ethical approval.

The approval is limited to this project: **00766/2014**. If you wish for a further approval to extend this project, please submit a re-application to the FMS Ethics Committee and this will be considered.

During the course of your research project you may find it necessary to revise your protocol. Substantial changes in methodology, or changes that impact on the interface between the researcher and the participants must be considered by the FMS Ethics Committee, prior to implementation.*

At the close of your research project, please report any adverse events that have occurred and the actions that were taken to the FMS Ethics Committee.*

Best wishes,

Yours sincerely

Kimberley Sutherland

On behalf of Faculty Ethics Committee

cc.

Professor Andy Hall, Chair of FMS Ethics Committee

Ms Lois Neal, Assistant Registrar (Research Strategy)

*Please refer to the latest guidance available on the internal Newcastle web-site.

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Appendix H: Information sheet for People with Parkinson's



Participant Information Sheet

Version: 2 Date: 20.03.2014

Study title:

Swallowing Changes in people visiting neurology clinics in Saudi Arabia: Perceptions and Practices

Invitation:

I would like to invite you to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully, and discuss it with others if you wish.

The first part tells you the purpose of this study and what will happen to you if you take part.

Later sections give you more detailed information about how the study works and your part in the study.

Ask us if there is anything that is not clear, or if you would like more information. Take time to decide whether or not you wish to take part.

Who am I?

My name is Kholoud Alhussain; I am a qualified speech and language therapist. I am studying for a doctorate in Speech Sciences at Newcastle University. My research is under the supervision of Professor Nick Miller, Dr Lindsay Pennington and Dr Katie Brittain at the Institute of Health and Society, Newcastle University.

What is the purpose of the study?

The overall aim of this study is to explore the experiences of people who visit neurology clinics in Saudi Arabia around probable changes to their swallowing and the possible impact of these changes on them and their families.

Why have I been invited?

You have been invited to take part in this study because you have visited the neurology clinic at King Fahad Medical City.

Do I have to take part?

No; taking part in this study is voluntary, and you are free to decide whether to join the study or not. If you feel you may like to join, I will explain the study in detail and we can go through the information sheet together. If you agree to take part of the study then I will ask you to sign the consent form. Please note that you are free to withdraw at any time without giving any explanation. Not taking part or leaving at a later stage will not affect the standard or types of care you receive now or in the future.

What will happen to me if I take part?

You will continue with your treatment with your neurologist and any other management you are receiving as normal, nothing will change. The only 'extras' from taking part in this study are the following:

1. I will sit with you in one of the clinics (or another place convenient to you) to talk with you about your experience of eating and drinking in relation to your health.
2. I will also talk to someone in your family who lives with you or visits often, or the person who provides care for you – to ask them about their impression of how your current health has affected your swallowing and how they themselves feel about issues around eating, drinking and swallowing treatment.
3. I will ask your clinician to pass to me details on your medical history and the medication you are taking, as well as the results from the rehabilitation assessments you had to go through.
4. I will interview your neurologist and therapists about possible swallowing changes. The interviews will not discuss individual people. You will not be identified in the discussion.

What are the possible disadvantages of taking part?

Taking part in the study will take about 1 hour of your time.

What are the possible benefits of the study?

This study may not help you directly, but the information I will get might help other people to improve their swallowing in the future.

The study will help doctors and therapists to understand potential swallowing changes to people visiting neurology clinics. The study will also help us understand if, and in what ways, swallowing treatments should be modified when used with people from different cultural backgrounds.

What if there is a problem?

If you have any concerns or worries about any part of this study, please ask to speak to me and I will do my best to answer all your concerns as much as I can. My contacts are at the end of this sheet. If you remain unhappy and wish to take your concerns further you can contact the supervisor of this research Professor Nick Miller, whose contact details are also at the end of the form.

If you remain unhappy and wish to formally register your concerns, you can do this through the King Fahad Medical City complains procedure.

Will my taking part in the study be kept confidential?

The information obtained while you are in this study, as well as the relevant information from your health records, will remain strictly confidential. The information gathered will only be seen by me as the investigator and the supervisory team (their names written below). No personally identifiable information relating to you will appear in any reports or presentations; nor will it be passed on to any other persons.

Who is organising and funding the research?

This project is part of PhD study which is taking place at the Institute of Health and Society at Newcastle University, GB. The funding comes from the government of the Kingdom of Saudi Arabia via the Cultural Bureau in London.

Who has reviewed the study?

This study was reviewed by the Research Ethics Committee at Newcastle University as well as Institutional Review Board at King Fahad Medical City, to protect your safety, rights, well-being and dignity.

What will happen to the results of the study?

Once the information of the tests and interviews collected, it will be analysed and written up as a PhD thesis. Part of this thesis will be published in medical journals and presented in conferences and seminars. We will feed back results to participants too.

Further information and contact details

You are encouraged to ask questions you wish, before, during and after your treatment. If you have any questions about the study please contact me at any time.

If you decided to take part of this study than please read and sign the consent form. You will be given a copy of this information sheet and the consent form to keep. A copy of your consent form will be filed in your patients notes, one will be filed with the study records and one may be sent to the research sponsor.

You have more time to think this over if you are unsure.

Many thanks for your time and efforts in reading this information sheet.

Principal Researcher:

Kholoud Alhussain

PhD student at Institute of Health and Society

Newcastle University

Baddiley-Clark Building, Richardson Road

Newcastle upon Tyne NE2 4AX

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Email: k.m.a.alhussain@newcastle.ac.uk

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Lecturer in Social Gerontology

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Baddiley-Clark

Newcastle upon Tyne NE2 4AX

Appendix I: Information sheet for Carers



Carer Information Sheet

Version: 2 Date: 20.03.2014

Study title:

Swallowing Changes in people with Parkinson's in Saudi Arabia: Perceptions and Practices

Invitation:

I would like to invite you to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully, and discuss it with others if you wish.

The first part tells you the purpose of this study and what will happen to you if you take part.

Later sections give you more detailed information about how the study works and your part in the study.

Ask us if there is anything that is not clear, or if you would like more information. Take time to decide whether or not you wish to take part.

Who am I?

My name is Kholoud Alhussain; I am a qualified speech and language therapist. I am studying for a doctorate in Speech Sciences at Newcastle University. My research is under the supervision of Professor Nick Miller, Dr Lindsay Pennington and Dr Katie Brittain at the Institute of Health and Society, Newcastle University.

What is the purpose of the study?

The overall aim of this study is to explore the experiences of people with Parkinson's around changes to their swallowing and the possible impact of these changes on them and their families. I am particularly interested in the possible effects of changes within the Saudi Arabia culture and the views of the health workers in Saudi Arabia on swallowing changes in people with Parkinson's and services to support them.

Why have I been invited?

You have been invited to take part of this study because you are closely related to or care for a person with Parkinson's and is following up in one of the clinics at King Fahad Medical City.

Do I have to take part?

Taking part in this study is voluntary, and you are free to join the study or not. If you feel you probably would like to join, I will explain the study in detail and we can go through the information sheet together. If you still agree to take part in the study then I will ask you to sign the consent form. Please note that you are free to withdraw at any time without giving any explanation. This will not affect the standard of care received by the person you are taking care of either now or in the future, or of any services you might need.

What will happen to me if I take part?

The study involves an interview with both you and the person with Parkinson's. The interviews will take 30 to 60 minutes and will involve questions about eating and drinking, mealtimes and preparation and possible swallowing changes noticed by you in relation to Parkinson's.

We also would like to let you know that the neurologist as well as the therapist who provide the person with Parkinson's treatment will take part in a focus group to discuss his/her opinions of swallowing changes for people with Parkinson's.

What are the possible disadvantages of taking part?

There are no disadvantages to taking part other than taking some of your time for the interview.

What are the possible benefits of the study?

I cannot promise you that this study will help you or the person with Parkinson's directly, but the information we obtain will help us to understand better how best to tackle swallowing problems for people with Parkinson's in the future.

What if there is a problem?

If you have any concerns or worries about any part of this study, please ask to speak to me and I will do my best to answer all your concerns as much as I can. My contacts are at the end of this sheet. If you remain unhappy and wish to take your concerns further you can contact the supervisor of this research Professor Nick Miller, whose contact details are also at the end of the form.

If you remain unhappy and wish to formally register your concerns, you can do this through the King Fahad Medical City complains procedure.

Will my taking part in the study be kept confidential?

If you consent to take part of this study, the information obtained will remain strictly confidential. The information gathered will only be seen by me as the investigator and the supervisory team (their names written below). No personally identifiable information relating to you will appear in any reports or presentations.

Who is organising and funding the research?

This project is part of PhD study which is taking place at the Institute of Health and Society at Newcastle University, GB. The funding comes from the government of the Kingdom of Saudi Arabia via the Cultural Bureau in London.

Who has reviewed the study?

This study was reviewed by the Research Ethics Committee at Newcastle University as well as Institutional Review Board at King Fahad Medical City, to protect your safety, rights, well-being and dignity.

What will happen to the results of the study?

Once the information of the tests and interviews is collected, it will be analysed and written up as a PhD thesis. Part of this thesis will be published in medical journals and presented in conferences and seminars. We will also feed back results to participants.

Further information and contact details

You are encouraged to ask any questions you wish, before, during and after your treatment. If you have any questions about the study please contact me at any time.

If you decided to take part of this study than please read and sign the consent form. You will be given a copy of this information sheet and the consent form to keep. A copy of your consent form may be sent to the research sponsor.

You have more time to think this over if you are unsure.

Appendix J: Consent form for People with Parkinson's

CONSENT FORM



Title of Project:

Swallowing Changes in people visiting neurology clinics in Saudi Arabia: Perceptions and Practices

Name of Researcher: Kholoud Alhussain

Institute of Health & Society

Newcastle University

Baddiley-Clark Building

Richardson Road

Newcastle upon Tyne NE2 4AX

Tel 0191 222 6459

Please initial

box

- 1 I confirm that I have read and understand the Patient Information Sheet dated 20/03/2014 (version 2) for the above study and have had the opportunity to ask questions.

- 2 I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without affecting my medical care or my legal rights.

3 I understand that the principal researcher will record details from my medical notes relevant to this research.

4 I understand that information from my medical notes may be looked at by the research group and by individuals from regulatory authorities or from the Ministry of Health who audit our research.

5 I agree that a member of my family can be contacted to ask them to take part in an interview for the study.

6 I agree to my Neurologist being informed of my participation in the study.

7 I agree to take part in the above study.

Name of Participant Date Signature

Name of Person taking consent Date Signature

Researcher Date Signature

Appendix K: Consent form for Carers

CONSENT FORM (Carer)



Title of Project:

Swallowing Changes in people with Parkinson's in Saudi Arabia: Perceptions and Practices

Name of Researcher: Kholoud Alhussain

Institute of Health & Society

Newcastle University

The Baddiley-Clark Building

Richardson Road

Newcastle upon Tyne NE2 4AX

Tel 0191 222 6459

Please initial

box

1 I confirm that I have read and understand the Carer Information Sheet dated 20/03/2014 (version 2) for the above study and have had the opportunity to ask questions.

2 I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without affecting the medical care of the person I am taking care of or our legal rights.

I agree to be interviewed by the principal investigator

3

4 I understand that the interview transcripts may be looked at by the researchers, individuals from regulatory authorities or from the Ministry of Health, where it is relevant to me taking part in this research.

5 I agree to take part in the above study.

Name of Participant Date Signature

Name of Person taking consent Date Signature

Researcher Date Signature
