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**Perspectives of Various Stakeholders
Towards the Role of Speech Language
Therapists in the Management of Infants
with Swallowing and Feeding Difficulties: A
Nationwide Survey in the State of Kuwait**

M.Sc. Clinical Speech and Language Studies
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ABSTRACT

Background

Dysphagia is commonly seen in preterm and low birth weight (LBW) infants and can heavily impact both the infant's and caregiver's quality of life. Speech Language Therapists (SLTs) have the duty and expertise to assess and treat infant's feeding and swallowing skills, as well as guide parents on safe feeding together with a multidisciplinary team (MDT). In Kuwait, the prevalence of such cases is high and SLTs were only recently added to the neonatal intensive and special care units (NICU/SCBU), in addition to out-patient clinics for infant monitoring. To date, no studies have examined understanding of SLTs' role in such settings.

Aims

The study was aimed at medical professionals and caregivers within the NICU/SCBU and out-patient clinics. The purpose was to 1) identify the level of awareness of SLTs' profession, 2) establish an understanding of the practices done, 3) and acquire suggestions for designing and delivering a training program that teaches parents safe feeding methods. Included as well was recognizing the levels of knowledge and comfort in service provision, and the level of caregivers' comfort in infant feeding.

Methods

Two anonymous web-based surveys (Qualtrics) were designed. Gatekeepers disseminate the surveys via convenience sampling to five hospitals located in four of six governorates. Descriptive and inferential data analysis were done using SPSS program, and content analysis for text-entry responses was applied.

Results

A total of 133 responses were from healthcare professionals and 21 from parents.' Healthcare workers generally had higher levels of awareness of SLTs' profession compared to caregivers. There was a strong association between levels of knowledge and comfort in the medical staff group. Most caregivers were somewhat comfortable on how their infant is fed. Shared themes between the two groups in terms of potentially creating a training program were to provide live and in-person demonstrations of feeding techniques and breastfeeding guidance, all within a short duration and group-based.

Conclusion

This study shows the targeted groups' knowledge of SLTs' discipline, present practices, and participants' opinions on training program content and mode of delivery. These preliminary data aid in determining steps to raise the level of awareness of SLTs' role in infant care and improve services via promoting MDT and increasing their clinical skillset.

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List of Abbreviations

Abbreviation	Full Description
AAP	American Academy of Pediatrics
ASHA	American Speech-Language-Hearing Association
CNS	Central Nervous System
CROSS	A Consensus-Based Checklist for Reporting of Survey Studies
FEDS	Feeding, Eating, Drinking, and Swallowing
GA	Gestational Age
HRIs	High Risk Infants
IASLT	Irish Association of Speech and Language Therapists
ICU	Intensive Care Unit
KOC	Kuwait Oil Company
KUNA	Kuwait News Agency
LBW	Low Birth Weight
LC	Lactation Consultant
MOH	Ministry of Health
NANT	National Association of Neonatal Therapists
NGT	Nasogastric Tube
NICE	National Institute for Health and Care Excellence
NICU	Neonatal Intensive Care Unit
NNS	Nonnutritive Suck
NS	Nutritive Suck
OT	Occupational Therapist
PCA	Post Conceptual Age

PFDs	Paediatric Feeding Disorders
PIL	Participant Information Leaflet
PMA	Post Menstrual Age
PT	Physical Therapist
RCSLT	Royal College of Speech and Language Therapists
SCBU	Special Care Baby Unit
SLP	Speech and Language Pathologist
SLT	Speech and Language Therapy/Speech and Language Therapist
SPSS	Statistical Package for Social Science
SSB	Sucking, swallowing, and breathing
UNICEF	United Nations Children's Fund
VFSS	Videofluoroscopic Swallow Study
WHO	World Health Organization

Chapter 1: Literature Review

1.1 Background

The purpose of this project is to identify current practices and beliefs of caregivers and healthcare workers in the management of infants with dysphagia in the State of Kuwait. This chapter provides an overview of (ab-)normal feeding and swallowing skills, impairments in these functions, caregivers of fragile infants, the SLTs role in neonatal care, current state of infants and SLTs in Kuwait, and guidelines on best practice services. Aims and objectives of the study are stated by the end of this chapter.

1.2 Normal feeding and swallowing in infants

Feeding and swallowing are two inseparable processes that promote social interaction and bonding between a child and caregiver (Lefton-Greif, 2008). *Feeding* refers to eating and drinking, encompassing sucking, chewing, gathering and preparing bolus for swallow. *Swallowing* is a highly complex integration of sensorimotor systems, oropharyngeal mechanism, cardiopulmonary system, gastrointestinal tract, and craniofacial and musculoskeletal structures (Averdson & Brodsky, 2002; Goday, 2019). It is divided into four stages: oral preparatory, oral transit, pharyngeal, and oesophageal phases.

In full term infants, the synchronizing of sucking, swallowing and breathing (SSB) are the expected early motor responses a healthy new-born is capable of and form the nutritive suck (NS) vital for survival and normal growth (Lau, 2015). A normal NS would occur at a rate of one suck per second, while a nonnutritive suck (NNS), which does not involve oral consumption of nutrients, is two sucks per second (Dewey, 2019). NNS is used as a predictor of successful oral feeding, a means for transitioning from gavage feeding to oral intake, and a way to reduce stress and manage painful procedures (Liaw, 2012). Successful feeding and swallowing require that an infant has stable physiological parameters and regulates his behavioural state. Behavioural organization is the infant's ability to regulate sleep and wakefulness in response to the environment and stimuli, and is an integral skill that reflects the competency of underlying neurologic state (Vandenberg, 2007).

Typically developing infants demonstrate normal feeding and swallowing through: oral feeding readiness, feeding in a quiet alert state, conserving energy throughout the feed, and maintaining normal vitals with no stress signs within a give and take exchange between infant and caregiver (da Costa et al., 2010; Lefton-Greif, 2008). This is achieved when an infant has a matured central nervous system (CNS) and fully developed organs and structure.

One of the first feeding related skill develops between 10 – 14 weeks gestation when pharyngeal swallow is observed (Table 1.1). This is followed by presence of NNS and eventually the coordination of SSB by 34 – 42 weeks. Fully matured lungs only form at around 36 weeks (Pineda et al., 2014; Delany & Arvedson, 2008).

A premature infant born < 37 weeks often faces a variety of issues such as feeding, swallowing, and respiratory support, requiring medical interventions like the use of assisted ventilators, analgesics for pain management, special feeding bottles and nipples, feeding therapy, family guided practice, and others. This is especially true for high-risk infants (HRIs) that may be born below 34 weeks and have a low birth weight (LBW), as well as neonatal asphyxia, neonatal sepsis, congenital anomalies, and surgery/anaesthesia exposure, amongst others (Jadcherla, 2016; Paolo, 2012).

Table 1.1 *Prenatal development of speech, language and swallowing related skills*

Age in weeks	Embryonic and fetal development	Development of speech, language and swallowing related skills
1 – 8 weeks PCA	Formation of major organs, including oral cavity, pharynx, larynx, and oesophagus	No development yet at this stage
Week 9 - Birth	Rapid growth, including development of neuropathways for oral sensorimotor function, swallowing and respiration	• 10 – 14 weeks: Pharyngeal swallow • 15 weeks: Nonnutritive suck • 21 weeks: forward tongue thrust • 18 – 24 weeks: True suckling and consistent swallowing • 28 weeks: Tongue cupping • 26 – 29 weeks: Development of taste and the ability of the lungs to breath in air • 28 – 33 weeks: auditory

		processing skills • 31 – 40 weeks: auditory perception of human speech • 36 weeks: fully developed lungs • 34 – 42: Coordination of sucking, swallowing, and breathing
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1.3 Dysphagia in infants

Dysphagia or swallowing disorder in infants is when the infant has difficulty regulating behavioural state organization when stimulated and when coordination of SSB is compromised due to congenital or acquired CNS damage (da Costa, 2010; Delaney, 2008).

Technological advances have led to increased survival rates of preterm and LBW neonates. In return, more medical complications, resource usage and affected quality of life have risen (American Academy of Pediatrics [AAP], 2008).

According to Lau (2015), oral feeding difficulties are present in 25–45% of typically developing infants and in 80% of developmentally delayed infants. Moreover, their consequences become evident as the infant grows (Jadcherla, 2016).

In a study from Cyprus by Senekki-Florent and Walshe (2021), the prevalence of paediatric feeding disorders (PFDs) in LBW infants was 36.5%. They identified six risk factors contributing to PFDs, which were birth weight, GA, bronchopulmonary dysplasia, neurological disorders, structural anomalies, and congenital heart disease.

The consequences of dysphagia in infancy include the following (Arvedson, 2002; American Speech and Hearing Association [ASHA], n.d.; Goday, 2019; Senekki-Florent & Walshe 2021; Dunitz-Scheer, 2009; Obeidat et al., 2009):

- Increased transition duration from gavage feeding to oral feeding
- Increased hospital length of stay and cost
- Compromised respiration

- Poor weight gain and hindered growth
- Stress and anxiety on both infant and caregivers
- PFDs
- Feeding tube dependency

Dysphagia is a serious issue for fragile infants and is exacerbated by prolonged hospital stay which may lead to iatrogenic complications (Sekar, 2010). This calls for the provision of best practice services to safely and efficiently manage fragile infants and their families.

1.3 Caregivers of critically ill infants

Infant feeding is a reciprocal process in which caregivers need to appropriately respond to the infant's oral readiness and stress cues in order to establish a positive experience. Parents are the primary care providers who necessitate adequate knowledge and confidence in safe feeding of their infants. It is crucial that they are integrated into the infant's management during the hospital stay and continue in follow up clinics if required (IASLT, 2021; Gibbins et al., 2008). Incorporating parents in the care of their child also promotes informed decision making, which is ethically appropriate (NICE, 2021). In addition, parents who are emotionally available to their infants help them fine tune self-regulation abilities as they grow, shaping both of them to be sensitive to one another's emotions, needs and motivations (Meisels, 2000). This will aid in the regulation of emotional communicative system, which is an important task for both the infant and parent.

Such demands from caregivers would mean the need for access to resources, as well as professionals meeting and addressing their mental, physical, and social stability needs. In the event that one of these factors are missing, it would impact infant's health. In addition, mothers in the postpartum period are often in emotional distress (Lee et al., 2011).

In line with Wigert and colleagues (2014), effective communication of NICU staff with parents helps to reduce feelings of loneliness, abandonment, and shouldering of undesired responsibilities. Additionally, a qualitative literature review by Obeidat et al. (2009), identified 14 articles describing parents' experiences in the NICU. Themes included feelings of alienation, despair, frustration, depression, and helplessness. The authors also reported increased levels of confidence and control in mothers with whom nurses communicated.

Communication characterized by honesty, caring attitudes and clear medical explanations are therefore important for optimal care as well as to preserve and promote neurological,

physiological, and emotional development (Kowalski et al., 2006; Guillaume et al., 2013; Altimier & Phillips, 2016).

1.4 SLTs' role in infant dysphagia management

The AAP (2008), stated that oral intake adequacy and safety are key factors that influence hospital length of stay, as well as maintaining normal body temperature and developing a mature respiratory control. It is also mentioned that oral feeding should be taught under the care of trained experts, stressing that a team of specialists including Speech Language Therapists (SLTs) are to be available for follow ups post hospital discharge for HRIs.

To further emphasize the above, the National Institute for Health and Care Excellence (NICE) highlighted in their guidelines (2017) that "infants born prematurely are at risk for speech, language and communication problems as well as feeding difficulties, and complex learning needs".

SLTs are trained in the assessment and treatment of feeding, eating, drinking, and swallowing (FEDS) impairments across all ages, as well as providing consultative services to the family. They are the preferred service providers for swallowing disorders (National Association of Neonatal Therapists [NANT], n.d.).

There are several elements that should be taken into account by healthcare workers when managing infants and their families. These involve providing an overall positive experience for them and reducing negative ones as many factors, such as the environment and medical staff's interaction, directly influence brain development (Gibbins et al., 2008). Pineda and colleagues (2014) found that private rooms with reduced noise and reduced caregiver-infant interaction resulted in delayed cognitive and language skills, suggesting the importance of early exposure to stimulation. Pain and stress are major factors in infant health and neurodevelopmental outcome. The Canadian Pediatric Society Statement (2000) recommended that healthcare providers must be able to identify signs of stress, anxiety and pain.

SLTs managing dysphagia in neonatal units begins with a thorough case history and clinical assessment of both structural and nonstructural causes of swallowing and feeding impairment (Jadcherla, 2016). This encompasses (Pineda et al., 2019; IASLT, 2021; NANT, n.d.; NICE, 2019):

- Instrumental assessment such as videofluoroscopic swallow study (VFSS)

- Assessing behavioral state organization
- Evaluating ability to maintain physiologic stability
- Oral-motor examination
- Evaluating NNS and NS maturity
- Recognizing oral feeding readiness
- Identifying stress cues
- Observing feeding and swallowing functions
- Assessing the coordination of SSB
- Determining suitable bottles/nipple flow rates to use
- Identify optimal feeding position in accordance to medical and developmental state
- Assessing impact of environmental factors
- Determining the caregiver's level of knowledge and confidence in feeding
- Recognizing medical comorbidities affecting feeding and swallowing such as Gastroesophageal Reflux Disease (GERD)
- Facilitating language acquisition through positive auditory exposure (e.g., talking or music).

Following assessment, the SLT may recommend when to provide oral opportunities, steps to transition to oral feeds, as well as parent and multidisciplinary team (MDT) education (IASLT, 2021; ASHA, 2004). SLTs could recommend oral-motor stimulation, though caution about its use is warranted (Arvedson et al., 2010). As stated previously, positive or negative alterations to brain development can result from external stimulation (Altimier & Phillips, 2016). Moreover, excessive therapy may lead to lethargy and reduced self-regulation (Ross et al., 2017). Parental guidance includes training to promote safe feeding, helping parents to identify stress signs, recognizing behavioural and physiological responses, suggesting suitable feeding positions and bottle/nipple flow rates to use, and provision of non-pharmacological methods to managing pain, gastroesophageal reflux disease (GERD) and other issues. SLTs and other healthcare workers who have obtained the International Board-Certified Lactation Consultant (IBCLC) certification can assess, guide and promote mothers on successful breastfeeding (IBCLE, 2008). In addition, there are breastfeeding protocols for SLTs to follow and are described in a literature review by Oliveira et al. (2019). They identified four protocols of breastfeeding evaluation from six articles including 1) observation of mother/baby bond and communication during breastfeeding, 2) breastfeeding evaluation using the adapted form of Assessment of Speech-Language Pathology of

breastfeeding, 3) feeding observation and evaluation, and 4) assessment of feeding with a cup, bottle as well as maternal breast.

Parents of HRIs and mothers assessed having postpartum depression would be advised to continue receiving services after hospital discharge for developmental monitoring and making referrals as appropriate (NICE, 2017; Beucke et al., 2019). Leniency on long term care may lead to exacerbated outcomes, undiagnosed cases, and reduced referrals (Beucke et al., 2019; Doyle et al., 2003)

1.5 Best practice guidelines for working with critically ill infants

The aim of NICU services is providing neuroprotective strategies that prevent neural cell death (McGrath, 2011; Altimier & Phillips, 2016), optimally implemented by an expert MDT (Figure 1.1).

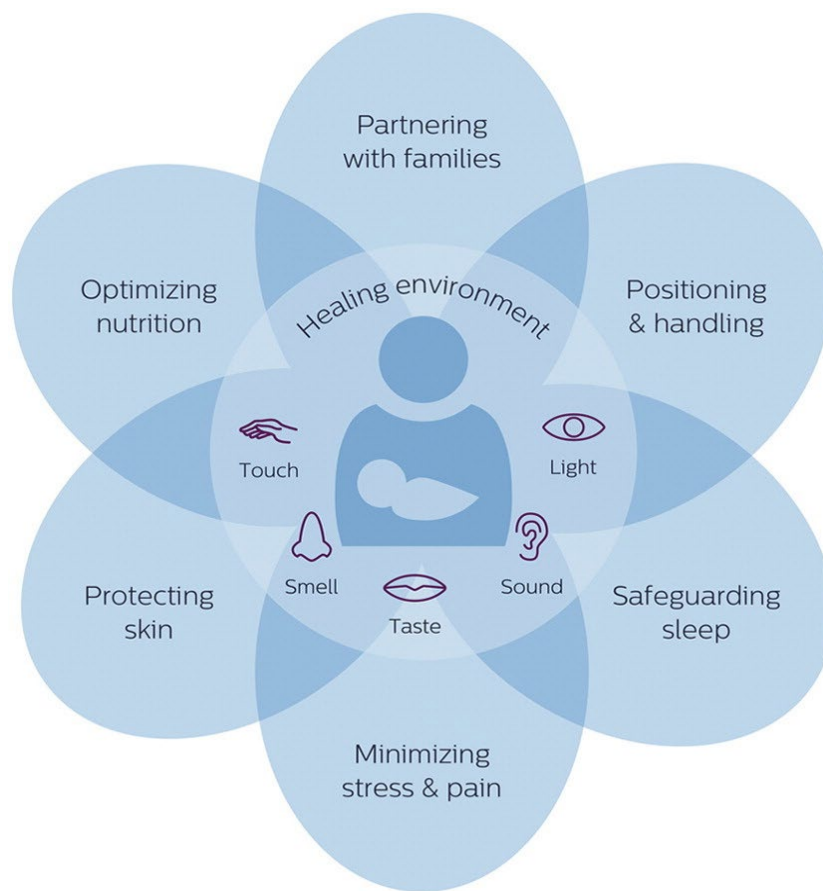
An SLT working with infants in the intensive and special care units has a duty to provide safe and evidence-based services by possessing a solid theoretical foundation in communication, swallowing and feeding evaluation and treatment, demonstrating competencies and undergoing extensive training and mentorship, all within the designated scope of practice and in conjunction with the MDT (NANT, n.d.; ASHA, n.d.; IASLT, 2021; Ross et al., 2017; Craig & Smith, 2020).

SLTs are also encouraged to engage in research and promote staff and public awareness where possible.

With respect to staffing recommendations and service planning, the following is advised:

“A collaborative multi-professional model of service planning strives to improve the infant and families neonatal experience and health outcomes during neonatal care reducing the pressure placed on the community services to provide long term support. Effective collaboration between the neonatal team members enables neonatal SLT’s to identify infants at risk and trigger necessary services” (Dow et al., 2017 as cited in The Royal College of Speech and Language Therapists (RCSLT) p.2).

Figure 1.1 *Neonatal Integrative Developmental Care Model*



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Note. From *The Neonatal Integrative Developmental Care Model: Advanced Clinical Applications of the Seven Core Measures for Neuroprotective Family-centered Developmental Care*. 16(4), 230-244, by Altimier & Phillips, 2016, Newborn and Infant Nursing Reviews. Copyright 2016 by Koninklijke Philips. Reproduced with permission.

1.7 Current situation of infants and SLT profession in Kuwait

In Kuwait, there is a high prevalence of assisted reproductive treatment (ART), mainly in-vitro fertilization (IVF) that poses, amongst other factors, an increased risk of preterm births and LBW infants (Sunkara et al., 2015; Cavoretto, 2018, McDonald et al., 2009, 2010). According to Dr Sami Al-Taher, head of obstetrics and gynecology department, in a Kuwait News Agency (KUNA) article (2019), Al-Jahra Hospital has treated 200 cases of IVF, 150 artificial inseminations were done, and 351 surgeries per day took place within the year of 2018. It was also reported that the infertility rate in Kuwait reached up to 15% of the population and that approximately 400 couples seek services from Reproductive

Endocrinologists for fertility consultation. This may very well increase the load of work in hospitals that provide neonatal intensive and special care, thereby potentially impacting the quality of the services.

An increase in HRIs demands the growth of a qualified MDT and an effort to spread awareness to both healthcare workers and prospective parents of ways to reduce such incidents as well as the optimum strategies in managing the medical comorbidities with which a preterm and LBW infant may present.

Deglutition issues are prominent in HRIs and an SLT, along with other professionals, play a significant role in establishing safe and efficient oral feeding skills, in addition to providing family guided care.

With regards to the SLT specialty, it is a relatively young profession in Kuwait as the field was first offered in 2003 at College of Life Sciences, Kuwait University (College for Women previously). A gradual growth in the number of graduates and services is occurring and research that is representative of the Kuwaiti population is required. One of the most recent developments done by the principal investigator and colleagues in September 2020 was the establishment of NICU and SCUB services in Adan and Maternity Hospitals. This process led to the realization that the level of awareness of what an SLT does in general and specifically with infants who have dysphagia, is low.

It is both observed by SLTs and reported by physicians that many caregivers seek help in the management of their infant's swallowing and feeding issues during, but mostly post discharge from the intensive care unit. Currently, infant care settings may have a team consisting of all or some of the following: paediatricians, neonatologists, nurses, laryngologists, gastroenterologists, neurologists, dietitians, physical therapists (PTs), occupational therapists (OTs), and lactation consultants (LCs).

1.8 Aims and objectives

The aims of this study were to:

- Identify whether steps should be taken to raise the level of awareness of the targeted groups regarding the SLT's scope of practice and what could be done to achieve this goal;

- Identifying current procedures used by healthcare workers and caregivers in handling infants with deglutition difficulties as reflected by the type of services available and the level of knowledge and comfort in infant management;
- Identify whether a training program that guides caregivers in the safe handling of their infants with dysphagia would be useful, as well as suggestions for designing and delivering it;
- Improve SLT services and promote a multidisciplinary and family-centered approach to treating infants with dysphagia.

The objective was to obtain representative data from medical staff and service consumers within both the NICU/SCBU and outpatient clinics for infant follow ups.

The medical staff and caregivers' knowledge of the SLT profession was assessed by whether the speciality's name is familiar to them or not, what caseloads are handled by them, and if they know what an SLT practices in general and particularly with neonates. It is hypothesized that the level of awareness of SLTs' profession amongst the Kuwaiti population is limited, namely in infant dysphagia management. Aside from what was mentioned above (1.7), this assumption also stems from two studies done in Kuwait. Both found poor levels of awareness about SLTs' occupation, along with limited knowledge on aphasia (Aljenai & Mackie, 2021) and stuttering (Al-Khaledi et al., 2011). A Canadian study by McHutchion et al., (2021) via web-based survey about dysphagia awareness revolving around its aetiology and management learned that there is poor level of knowledge in 71% of non-healthcare workers (n=269), and in 29% of healthcare participants (n=105). Sample representativeness was one of the issues as most of the respondents were younger individuals of higher education with less exposure to dysphagia cases and majority were females. Survey biases like non-response and selection bias were also amongst the limitations mentioned.

1.9 Summary

There is a high percentage of dysphagia presence in neonates, especially those born prematurely. The fact that they need hospitalization puts them and their caregivers at risk of developing stress and unwanted outcomes. Both infants and their caregivers necessitate utmost attention and care by an expert MDT. An approach towards this goal is promoting awareness of the SLTs' profession in Kuwait and incorporating them as essential team members of care. In addition, there is a lack of such studies in Kuwait regarding infant

feeding and swallowing management. It is, therefore, of importance to procure information addressing the topic with the end result of improving clinical performances.

Chapter 2: Methods

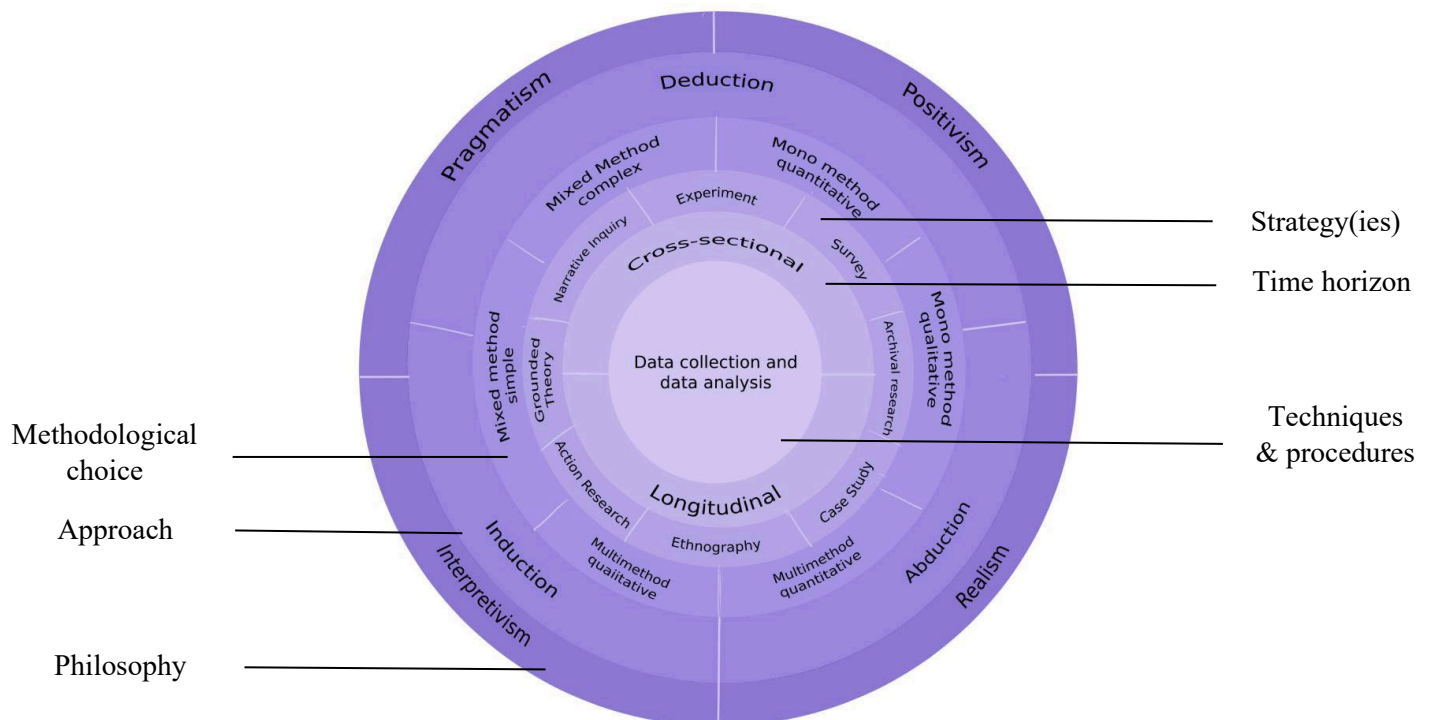
2.1 Introduction

This chapter addresses the study design chosen, justification and limitations of it, procedures required to conduct the study, and analysis approach used. Participants recruited for this study were healthcare professionals and caregivers. The professionals were physicians, PTs, OTs, LCs, SLTs, and nurses. Caregivers included mothers, fathers or guardians. A Consensus-Based Checklist for Reporting of Survey Studies (CROSS) was followed (Sharma et al., 2021).

2.2 Research Philosophy

A set of beliefs and suppositions on how knowledge is created are what define *research philosophy* (Saunders et al., 2019). It contributes to a study's credibility if well planned and reflects the choices of methodology, data collection techniques and data analysis processes (Figure 2.1).

Figure 2.1 *Research philosophy*



Note. Adapted from *Research Philosophy*, by J. Dudovskiy, n.d., Business Research Methodology. (https://research-methodology.net/research-philosophy/#_ftn1).

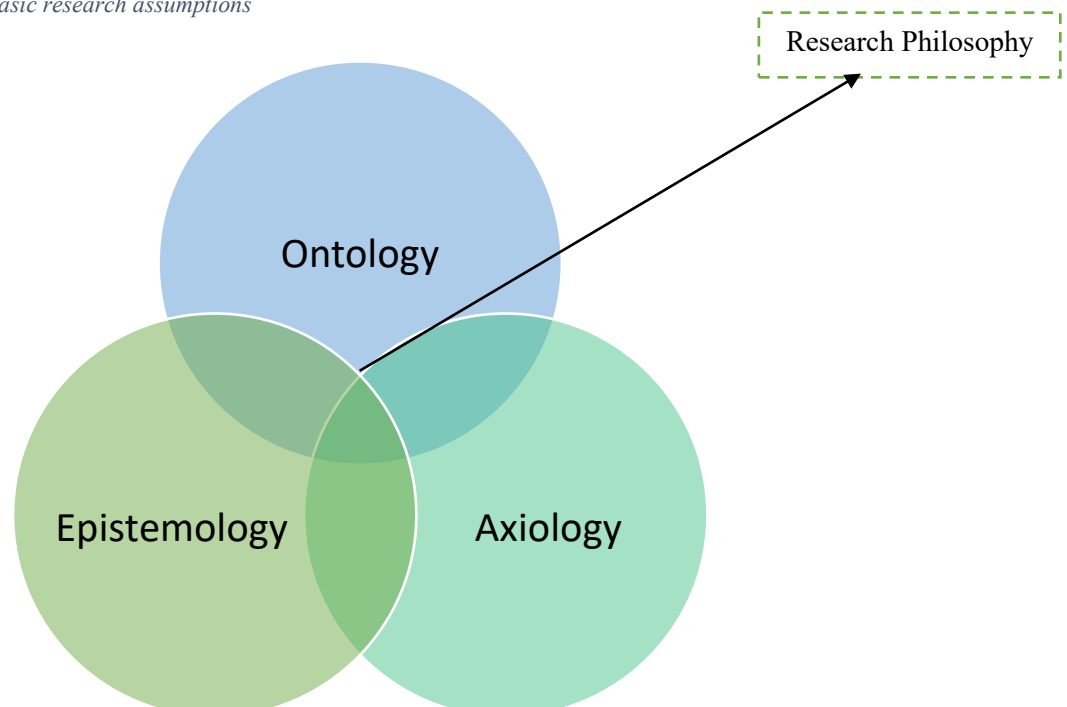
Saunders et al. (2019) explained three basic research assumptions, which are ontology, epistemology and axiology (Figure 2.2).

Ontology refers to what we perceive the nature of reality to be and consists of opinions, knowledge, values, actions, and other objects. (Creswell & Poth, 2018). Ontological assumptions shape the way objects of interest are viewed. An intensive care unit (ICU) for neonates can be examined by the environment itself, the people that work in it, and the policies being implemented, to mention a few.

Epistemology relates to assumptions of knowledge, what is considered to be rigorous knowledge and how it may be relayed to others (Saunders et al., 2019). A multitude of resources can be seen as legitimate knowledge such as facts, perspectives, narratives, and numerical data.

Axiology pertains to ethics and values of a researcher and how they may affect a study's overall method of conducting it (Saunders et al., 2019). Purpose of a research also reveals axiological stance and on what basis were such aims made (1.7).

Figure 2.2 The three basic research assumptions



To answer the research's queries and potentially invoke future plans to improve patient care, pragmatism best fulfills this role. The philosophy of *pragmatism* is to recognize that the complex reality is generated by ideas (ontology), focuses on issues and problem solving

(epistemology), and is value-driven (axiology). It uses a variety of relevant methods to investigate the objects of interest. Theories, concepts, and study findings are seen as means to reach practical solutions (Kelly& Cordeiro, 2020, Saunders et al., 2019). This philosophical orientation is characterized by flexible inquiry and is ideal for studying dynamic organizational processes that is formed by differing knowledge, experiences, and behaviors pre-existing in individuals or influenced by external reality.

Since infant feeding and swallowing management provided by hospitals of Kuwait was the topic of interest, the focus was on obtaining an understanding of professionals' and service consumers' views, experiences and actions within the NICU/SCBU and outpatient clinics. They are targeted to generate preliminary descriptive information of what is being practiced by them and how such information may aid in eliciting positive amendments in health settings.

To prevent gaps in information, mixed methods was operationalized as it makes clear the value of using both quantitative and qualitative data (Morse, 2009). Such method ensures multiple aspects of the topic under examination are considered and is in line with pragmatism.

This study used the convergent mixed methods design, in which quantitative and qualitative data are collected, individually analysed, and outcomes are compared and contrasted (Creswell & Creswell, 2018).

2.3 Ethical Approval

Ethical approval to conduct the study was acquired from the School of Linguistic, Speech and Communication Sciences, Trinity College Dublin (Appendix F), as well as from the research committee in Ministry of Health Kuwait (MOH) for the chosen health regions (Appendix E). The approval from the research committee in Kuwait was forwarded to the corresponding hospital directors to ask for permission in principle to conduct the research. Finally, it is delivered to departments in which the NICU/SCBU fall under in terms of administration (Appendix A). Where possible, individual meetings with each hospital director/department manager were completed in order to explain the study, formally request for gatekeepers (Appendix L), and acquire permission to recruit participants both in-person and electronically.

2.4 Study Design

2.4.1 Survey design

Guidelines and checklists for designing and administering surveys (Bell & Waters, 2018; Choi & Pak, 2015), as well as biases to avoid were followed (Table 2.1). They provide instructions as to how to enhance survey readability, understandability and response rate. Additionally, reliability and validity are further increased by minimizing errors and maximizing accurate results. This research utilised as a cross-sectional, observational study design. Two anonymous, self-administrated electronic questionnaires were developed using Qualtrics for this purpose. They consisted of two sections: the first relates to demographic information and general knowledge of an SLT's profession. The second section pertains to swallowing and feeding issues, as well as the participants' feedback regarding developing a training program that guides caregivers on safe management of an infant's swallowing and feeding difficulties (Appendices I and J).

The staff survey had 13 questions, while the caregiver survey had 18 questions (Appendix J). Themes for both questionnaires were matched and reflected research aims. Appropriate language level was used for every targeted group. Multiple revisions with the research supervisor were done before finalizing the questionnaires. In addition, the caregiver survey was translated to Arabic and reviewed by two native speakers to ensure clarity (Appendix K).

The surveys encompassed both open-ended and closed-ended questions that yielded quantitative and qualitative data. All questions had force response applied to them in order to avoid missing data. Free text responses were included as they allow the participants to express their opinions towards the type of guidance they might have received to help manage their infant with feeding and swallowing issues, describe how they think an SLT can be of help, and provide suggestions for the content and mode of delivery of a training program.

Skip and display logics were implemented on certain questions and are summarized in Appendices B, C, and D.

The survey web addresses were shortened using bit.ly for ease of noting. The staff survey link was <http://bit.ly/staffsurvey>, while the caregiver survey link was <http://bit.ly/caregiversurvey>.

Table 2.1 *Designing and administering survey checklist*

No.		
1	Ethical approval	Obtained from necessary stakeholders.
2	Deciding on information needed	The questionnaires only contained items that fulfil the study's aims and objectives, excluding unnecessary ones.
3	Deciding on study approach	Obtaining quick and large data set with the objective of identifying steps to amend infant services on a country-wide level is best achieved via electronic survey.
4	Wording questions	- Double-barrelled, ambiguous, leading, blunt, and complex questions were avoided. - Jargon words were not used for the caregiver group, with a few included in the healthcare staff group. - Uncommon and vague words were not used. - Questions regarding beliefs and behaviours were clearly phrased. - The phrase "in recent memory" for the healthcare workers' survey was used in order to identify in-trend practices. - Word choices were closely matched in both surveys to obtain similarly themed results. - Prestige-bias, recall-bias and sensitive questions were included in order to identify current practices in infant management in Kuwait. - Positive satisfaction may occur but chances are lessened due to participant anonymity.
5	Checking for word ambiguity, imprecisions and assumptions	The appropriate language level was used for each of the targeted groups. This process involved several revisions with the research supervisor, piloting, and revision of the translated caregiver survey by two Arabic speakers.

6	Deciding on question type	A variety of question types were used.
7	Deciding on question order	Questions pertaining to demographics, level of awareness, and current practices, along with suggestions for a training program were separated to three pages to reduce question order effect.
8	Writing clearly presented instructions	Questions that allowed multiple answers had “select all that apply” written at the end of each question. In addition of including “0: being least, and 100 being most” for questions with sliders as answers.
9	Survey layout	- Horizontal response layout and left response choices were used since it is less confusing for self-administered surveys. - Separate scales for similar items were created to lessen confusion. - The surveys were found to take 10 minutes, give or take, to complete or more for those who wish to elaborate further on their experiences. None of the piloted group reported response fatigue.
10	Deciding on the sample	Inclusion and exclusion criteria were clearly defined.
11	Piloting and making necessary changes	Piloting followed by cognitive interview and survey adjustments were done.
12	Analysis methods	Descriptive, inferential, and content analysis were used.
13	Survey dissemination	- Detailed plan on distributing the survey was devised. - No question that addresses unacceptable disease, exposure, faking bad/good, or cause harm such as embarrassment are asked.

14	Survey completion	Respondents were given the freedom to complete the survey at their own pace. Completion progress of each participant can be seen on Qualtrics.
15	Non-response error	Force-response was applied on the survey questions.
16	Recording responses	Automatically compiled and described in Qualtrics.
17	Use of simple and required statistical analysis	Qualtrics and Statistical Package for Social Science (SPSS) were used for the statistical analysis.

2.4.2 Question design

Based on the research objectives, the survey had four themes. The first pertained to demographic information. The second one looked into the level of awareness of the SLT's profession in general and in managing feeding and swallowing difficulties. The third contained questions about prevalence of deglutition issues in infants, the current practices in managing them, and which of the medical staff mostly handles them. Finally, the fourth theme addressed designing a training program for guiding caregivers in the safe feeding methods, what the respondents think it should contain and preferred mode of delivery.

Bell and Waters (2018) have listed various questions types. For this study, a blend of question types was selected for the above purposes. This includes closed-ended questions (yes, no), open-ended questions (free text entry), categorical questions, list/multiple choice questions, Likert scales, and questions with sliders as answers. Table 2.2 explains the rationale behind each question for both targeted groups. Questions with Likert scales were restricted to five answers so as to avoid bias context (Glasow, 2005). The questions asked measured participants' description of people and services, response to ideas, plus levels of knowledge and comfort.

The two final questions in both surveys addressed content and mode of delivery of a training program and have complementary qualitative and quantitative data. Questions with multiple choices permit qualitative input.

Table 2.2 Survey questions and rationale

Staff		Caregivers	
Questions	Rationale	Questions	Rationale
Q1: Job title	Identify service provider in order to know who mostly manages infants with dysphagia.	Q1: Main caregiver	Identify whether the caregiver is a mother, father, or guardian and how each may have different perspectives on the topics addressed.
Q2: Place of work	Identify which setting the staff works in for descriptive and inferential analysis purposes, as well as to direct them to questions of relevance.	Q2: Where the infant is currently	This is asked to direct the caregiver to the questions of relevance.
Q3: SLT profession		Identify the number of participants that either heard or did not hear of SLT profession.	
Q4: Knowledge of SLT		Identify respondents' level of awareness and knowledge of SLTs field of specialty.	
Q5: Age groups		Identify what age groups the participants think an SLT manages.	
Q6: Referrals within NICU/SCBU	Prevalence of infants with swallowing and feeding issues within the NICU/SCBU	Q6: Observed swallowing concerns within the NICU/SCBU	Identify whether they personally observed swallowing and feeding issues in their infants or not.
Q7: Swallowing issues post	Prevalence of infants with swallowing and feeding issues post discharge	Q7: Reported swallowing	Identify whether or not they were told by the medical staff or a specialist outside of the hospital that their

discharge		concerns within NICU/SCBU	infant has swallowing or feeding difficulties. This may reflect how much the staff is able to recognize such issues.
Q8: Services provided	Identify what type of services the medical staff would provide infants with swallowing and feeding issues.	Q8: Observed swallowing concerns post discharge	Identify whether they observed any swallowing or feeding issues post discharge or not. If they did, this will raise the question of how was the feeding done during hospital stay, what changed, and did the staff do any form of education or guidance for the caregiver?
Q9: Level of comfort	Identify how would the medical staff rate their level of comfort in assessing and treating infants with swallowing and feeding issues, and in counselling caregivers.	Q9: Follow ups post discharge	Identify whether the medical staff would recommend any follows ups post discharge due to swallowing and feeding issues or not.
Q10: Level of knowledge	Identify how would the medical staff rate their level of knowledge in assessing and treating infants with swallowing and feeding issues, and in counselling caregivers.	Q10: Guidance given	Identify whether any guidance was given to the caregivers who have an infant with swallowing and feeding issues or not.
		Q11: Person who gave guidance	Identify the healthcare worker who provided the guidance and measure the prevalence.
		Q12: Level of satisfaction	Identify how satisfied the caregiver was from the guidance given to them.

		Q13: Type of guidance given	Identify the type of guidance given, which will contribute in knowing the current practices done in infant swallowing and feeding management.
		Q14: Actions taken	Identify what the caregiver has done to help their infant feed well.
		Q15: Level of comfort	Identify how comfortable is the caregiver on how the baby is fed. This may indicate several factors such as experience, whether they received guidance or not, and perhaps if the swallowing and feeding issues are persisting.
Q11: SLT services	Identify what the medical staff thinks an SLT's role is in helping infants with swallowing and feeding issues	Q16: SLT support	Identify what the caregivers think an SLT's role is in helping infants with swallowing and feeding issues.
Q12/17: Training Program content		To acquire the respondents' opinion on a training program content that will aid in developing one in the future.	
Q13/18: Training program delivery		To acquire the respondents' opinion on a training program mode of delivery that will aid in developing one in the future.	

Key: ☐ Demographics ☐ Level of awareness ☐ Current practices ☐ Suggestions for a training program

2.4.3 Survey piloting

The surveys were sent to seven healthcare workers and five caregivers, proceeded with a cognitive interview and/or feedback request of the design, logical errors, question formation, answers chosen, and spelling or grammatical mistakes. The seven healthcare workers consisted of five SLTs and two physicians, with another physician requested to partake in the piloting, but then withdrew. As for the caregivers, three had infants discharged after receiving care from the hospital, while the other two were still in the hospital. All of the respondents were satisfied with the survey and did not consider any of the items offensive or covering sensitive issues (Bell and Waters, 2018). Two SLTs had inquiries and comments about questions 15, 16, and 17. One SLT understood two survey questions as being identical due to their phrasing, so this was addressed by explaining the difference. Question 17, which asked “What services do you think a Speech Therapist provides in the management of infants with swallowing and feeding issues?”, is to appear to all professions except for SLTs since it addresses them. This was corrected for the final version of the survey by adding a display logic.

The surveys were estimated to take around 10 minutes or more for those who wish to elaborate on their experiences and opinions.

2.4.4 Validity, reliability and biases

Validity of the survey reflects how accurate the questions measure the desired outcome and the sample representativeness. There are three types of validity identified by Creswell & Creswell (2018) and they are: 1) content validity, which is whether the items of a survey measure the intended content, 2) concurrent validity, that is whether results correlate with one another and if score anticipate a criterion measure, and 3) construct validity that refers to whether the items measure hypothetical concepts. Possible threats are that the sample size is small, the questions are not clear or are understood differently by the participants, the lack of consistency in the results obtained, and influenced answers of participants.

Reliability, on the other hand, means how consistent the measurements are (Cobern & Adams, 2020). Internal reliability is the most vital type of reliability and it concerns the degree to which a group of survey items behave in a similar matter (Creswell & Creswell, 2018).

Biases refer to consistent errors that lead to a certain outcome over another and is a result of selected sampling strategy, survey and question design, as well as questionnaire

administration (Choi & Pak, 2005). A summary of some biases types from Choi & Pak are illustrated in Table 2.3 below.

Table 2.3 *Types of biases*

Source	Bias
Question design	- Wording issues: ambiguous, complex, double-barrelled, and leading questions - Insufficient information: use of insensitive measures - Faulty scale: scale format and missing intervals - Intrusiveness and inconsistency: sensitive question and change of wording or scales
Questionnaire design	- Issues with formatting: text alignments - Long questionnaire: response fatigue - Imperfect survey structure: skipping question
Administration of questionnaire	- Interviewer not objective - Respondent's subconscious reaction - Social desirability/prestige-bias - Unaccepted disease and exposure - Recall and prestige biases - Respondent's learning: hypothetical guessing

To alleviate the possibility of small sample size, the hospitals chosen to distribute the surveys were ones that had large caseloads and adequate staff size to recruit as much healthcare practitioners and caregivers as possible. There were six hospitals approached, which were Adan, Alfarwaniya, Aljahra, Jaber Alahmad Alsabab, KOC (Kuwait Oil Company), and Maternity hospitals. Permission to conduct the study was given by five hospitals instead and were located in four of six governorates.

As mentioned above, piloting the survey ensured that the questions were understood by all of the respondents and that there were no major issues that necessitated correcting, except for questions 15 and 16 in the staff survey.

Since the survey was self-administrated, it reduced the possibility of stakeholders' answers to be affected by others (Nardi, 2018).

Strategies to avoid different types of biases are mentioned previously in Table 2.1 in wording questions, survey layout and survey dissemination. In addition, sensitive measures were used such as five-point (odd number) Likert scale and sliders with a range of 0 – 100. This alleviates forced choices and provides enough discriminating power. The use of odd numbers of choices may yield neutral answers in comparison to even numbered choices (Choi & Pak, 2005). Sufficient and varying age ranges were given in question four addressing the age groups delt by SLTs.

2.4.5 Participants

To reduce biased responses and non-response rate (Taherdoost, 2016), all participants of relevance were included. Medical students are recognized as a group that will contribute to the research objectives, but are excluded due to time constraints and the difficulty of handling a possibly large data set. Nurses were included later in the study during the data collection phase due to a gatekeeper sending the survey link to them. Other gatekeepers were thus contacted to share the survey with nurses. Participants of interest were divided to two groups. The first are the medical staff that work with infants receiving intensive or special care, and/or in the outpatient clinics. They included physicians, PTs, OTs, SLTs, LCs, and nurses. The second group are caregivers who have infants in the NICU or SCBU, or are discharged from the hospital. Those discharged may or may not be following up in outpatient clinics. This group encompass parents or guardians.

A convenience non-probability sampling method was chosen so that only the desired groups' input is gathered. Table 2.4 below includes the inclusion and exclusion criteria.

There are no accurate numbers that help determine what sample size is required for the outcomes to be representative, but it is indicated in the table provided by Krejcie and Morgan (1970), as well as Salant and Dillman (1994) that the sample size for large populations generally does not exceed 384 participants.

Table 2.4 *Participant inclusion and exclusion criteria*

Groups	Inclusion	Exclusion
Medical staff	- Qualified Physicians, PTs, OTs, SLTs, LCs, and nurses - Must be working in the NICU, SCBU, and/or outpatient clinic for follow ups post discharge	- Medical students working/practicing in NICU, SCBU, and/or outpatient clinic - Any medical staff that does not provide services to infants and their families
Caregivers	- Mother, father, and guardians of infants - Infants include those residing in the NICU or SCBU, or those discharged after receiving intensive or special care	- Any individual who does not have/did not have an infant in the NICU or SCBU

2.5 Data collection procedures

Data collection began on February 16th, and ended on the 6th of May. Follow ups and reminders were done throughout the data gathering period. A total of nine gatekeepers with some of them known to the principal researcher were in charge of distributing the survey. Five of them were SLTs, and four of them were physicians/departmental managers from different hospitals, which makes it easier for them to collect data from where they already work. They were instructed to briefly and plainly describe the study. Furthermore, the caregiver questionnaire was distributed by trained healthcare professionals sensitive to working with vulnerable individuals. Participants were advised to avoid taking the survey more than once.

The survey link that targets the medical staff was disseminated via WhatsApp by head physicians/heads of departments. In comparison to emails, WhatsApp is the most widely used and culturally accepted means of communication in Kuwait. No phone numbers were obtained by the principal investigator since the gatekeepers already possess the contact details of their fellow colleagues for work purposes. The study's aims were explained verbally, whereas a short message was attached to the survey link should it be shared in a WhatsApp

group that some departments have created. This message was as follows: “Please consider taking this survey about management of feeding, eating, drinking and swallowing difficulties in infants”.

The caregiver group had two questionnaire distribution methods listed as follow:

Method 1: Caregivers who are physically present in the hospital, whether attending to their infant residing in the ICU, or following up in outpatient clinics, were approached by the gatekeepers. If they agree to participate post verbal explanation of the study, a copy of the patient information leaflet (PIL) is given in printed form (Appendix H) or via AirDrop (Appendix G). File sharing between Apple devices in close proximity is possible with AirDrop and does not require the transfer of personal information. Most of the Kuwaiti population own iPhones.

Method 2: For those not physically present in the hospital due to their infants being discharged or having no upcoming appointments, they were communicated with over a work phone line and upon agreeing to take part in the study, were given three options to access the survey. These were 1) dictating the shortened survey link for them to write down, 2) sending the PIL through email, 3) or sending the PIL by WhatsApp.

Given the time constraints, the fact that the principal investigator will not have direct access to the participants due to being in a different country from them, and to observe, describe as well as measure knowledge and perspectives of a large population (Suzanne, 1998), online survey dissemination was chosen as the most convenient method for data collection. It provides initial information of chosen groups when secondary resources are not available (Salant & Dillman, 1994).

Surveys are cost-effective, cover wide latitudes and are suitable for precise generalizability, permit creating standardized questions, ideal for knowing stakeholders’ perspectives, time efficient, reassure anonymity; making it better for sharing personal and sensitive information, address more than one topic, and allow freedom to complete it at the participant’s own pace (Salant & Dillman, 1994, Nardi, 2018). Moreover, mixed methods approach is made easier when using surveys as no issue regarding unequal sample sizes for quantitative and qualitative data sets is present. They are, however, subjected to certain errors such as item nonresponse, influenced answers by other consulted respondents, low return rate, and clarification of responses cannot be asked for (Safdar et al., 2016, Nardi, 2018).

Clarifications are possible with interviews and focus groups, for which they were taken into consideration as other means of fulfilling the research's aims. Both methods yield rich descriptive and interpretive data set in a natural environment. Carter et al. (2014) mentioned that the drawbacks of such approaches include the long durations needed for data collection, dialogue transcription, and information analysis. In-depth interviews may provide comfort for the subjects to share sensitive and controversial ideas, contrary to focus groups. Focus groups, though, generate dynamic interactions amongst participants. This, in turn, leads to a multitude of novel outcomes and diverse forms of communication that can also pose as quite a task to transcribe. Furthermore, some gatekeepers have clearly stated to the principal investigator that interviews would be difficult to organize due to the nature of an ICU setting.

2.6 Data Analysis

2.6.1 Statistical analysis

Data analysis is an important aspect that reflects the credibility and successfulness of a survey (Glasow, 2005). Statistical calculations are acquired from Qualtrics and exported into word document. Participants' responses are exported into SPSS and adjustments to variable type were made. Descriptive and inferential analysis were applied. It includes measurements of frequency, mean, standard deviation, range, and Spearman's rho correlation analysis. Outcomes were summarized in either graphs or tables.

The results from the last two questions in both surveys utilize a side-by-side comparison of quantitative and qualitative data (Creswell & Creswell, 2018).

2.6.2 Content analysis

Content analysis can be described as a tool that identifies particular words or concepts within a qualitative data set to quantify and generate meanings and associations amongst keywords. It is a reflective process and is preceded by underlying context interpretation (Hsieh & Shannon, 2005, Erlingsson & Brysiewicz, 2017). Common and shared themes amongst participants are coded/labeled and categorized for each group. Frequency count for every category was done and inferences were made.

2.7 Ethical consideration

Potential difficulties of obtaining caregivers' responses are the fact that they may be mentally and physically distressed and that they have critically ill infants. It is especially a delicate

situation for mothers who are in the postpartum period. Nonetheless, their perspectives serve as valuable information that can help identify any changes required in SLT services and help to improve it.

2.7.1 Respect for Autonomy and consent

For a person to be autonomous, he/she must fulfil three conditions, which are intentionality, understanding, and not being influenced by others. (Beauchamp & Childress, 2019; Finnegan & O'Donoghue, 2019). It may be argued that the healthcare workers would feel obliged by gatekeepers of higher authority to partake in the study. Similarly, gatekeepers who are clinicians may compel caregivers to participate. Additionally, comprehension and decision making could be impacted by caregivers' current mental and physical states as mentioned above (Mental Capacity Act, 2021). Beauchamp and Childress, though, stated that an autonomous action does not necessitate full understanding. The dynamic specific consent model was followed (Wiertz & Boldt, 2022) and explicit consent was acquired after verbal/written explanation of the study (Section 2.5). The first pages of both surveys contained the option to consent or withdraw from the study. Any individual who does not consent to participating will be directed to the end of the survey. Withdrawal was also possible at any stage of the questionnaire. Furthermore, the PIL was presented separately for caregivers. The first page of the surveys and PIL (Appendix G and Iarabic) mentioned the participants' rights, associated benefits, that participation is completely voluntary, and other relevant info.

2.7.2 Anonymity and confidentiality

To maintain confidentiality is to avoid further disclosure of already generated information within a confidential relationship (Beauchamp & Childress, 2019). This can be argued from a consequence-based point of view, and from privacy rights perspective. An undesired outcome of breaching confidentiality could be the loss of trust between the confider and confidant, leading to participant reluctance to join a research study. The right for autonomy and anonymity are seen by other parties to form the principle of confidentiality and are to be respected. As mentioned previously, gatekeepers were assigned to recruit participants, thus no personal data is obtained by the principal investigator. Gatekeepers who recruited caregivers over the phone accessed, but did not collect phone numbers. Sensitive information regarding caregivers' infants and their health needs are indeed captured and stored, however,

none of the respondents can be identified by the survey questions. In addition, the survey has been configured such that the IP address of the participants will not be captured.

2.7.3 Beneficence and non-Maleficence

It is essential that a person does not do harm, removes it, prevents it, and actively promotes good (Beauchamp & Childress, 2019). Harm is a broad term that may refer to bodily or mental damage, inconvenience, or obstruction of interest. Non-maleficence is an obligation to adhere to at all times, unlike beneficence that may be partially followed. To do good is to be of benefit and help to others. Amongst the code of ethics ASHA listed, educating professionals of other disciplines and the public of SLTs' scope of practice and various conditions dealt by them is a duty to be upheld. It falls under public beneficence and is an aim sought after via this research study. Outcomes may contribute to taking steps in raising the level of awareness of SLTs' involvement in managing feeding and swallowing difficulties in infants and the betterment of services.

In the event participants expect additional services post completing the survey, it is made clear in the consent page and PIL that no extra assessment, treatment and counselling services are to be added. The gatekeepers were also instructed to confirm this point should the participants inquire. Additionally, the study's aims and questions were elaborated on with the gatekeepers. The gatekeepers' adequate understanding of the study helps avoid any probable misleading assumptions by the respondents.

The stakeholders are informed that no direct benefit shall be attained from completing the survey, but their participation is a step closer to knowing what improvements are needed and the probability of expanding the SLT services to other hospitals in Kuwait.

2.7.4 Justice

Justice may be interpreted as "fair, equitable, and appropriate treatment in light of what is due or owed to affected individuals and groups" (Beauchamp & Childress, 2019, p.196). Incorporating stakeholders of relevance is mandatory in health researches as it yields novel and beneficial knowledge. In order to implement the principle of justice and achieve the project's goals, both healthcare workers and caregivers were given equal opportunities to actively take part in the study. This is also in agreement with the pragmatism philosophy.

To exclude caregivers that form a vulnerable group is to deprive them the chance of sharing their perspectives on the topic of interest. Forming an understanding of current practices and

seeking to improve patient care necessitates that all involved are heard and taken into account, especially that they are what form dynamic health organizations.

2.8 Summary

Two electronic surveys consisting of 13-18 questions were disseminated over a period of around three months via convenient sampling method and estimated to take approximately 10 minutes to complete. The study design was thoroughly thought through and outlined. Ethical considerations for both targeted groups were taken into account. Descriptive and inferential statistical analysis were generated for the quantitative data, while content analysis was used for qualitative responses.

Following this chapter are the data analysis results.

Chapter 3: Results

3.1 Introduction

This section details the outcomes of the surveys in terms of descriptive, inferential and content analysis.

3.2 Responses

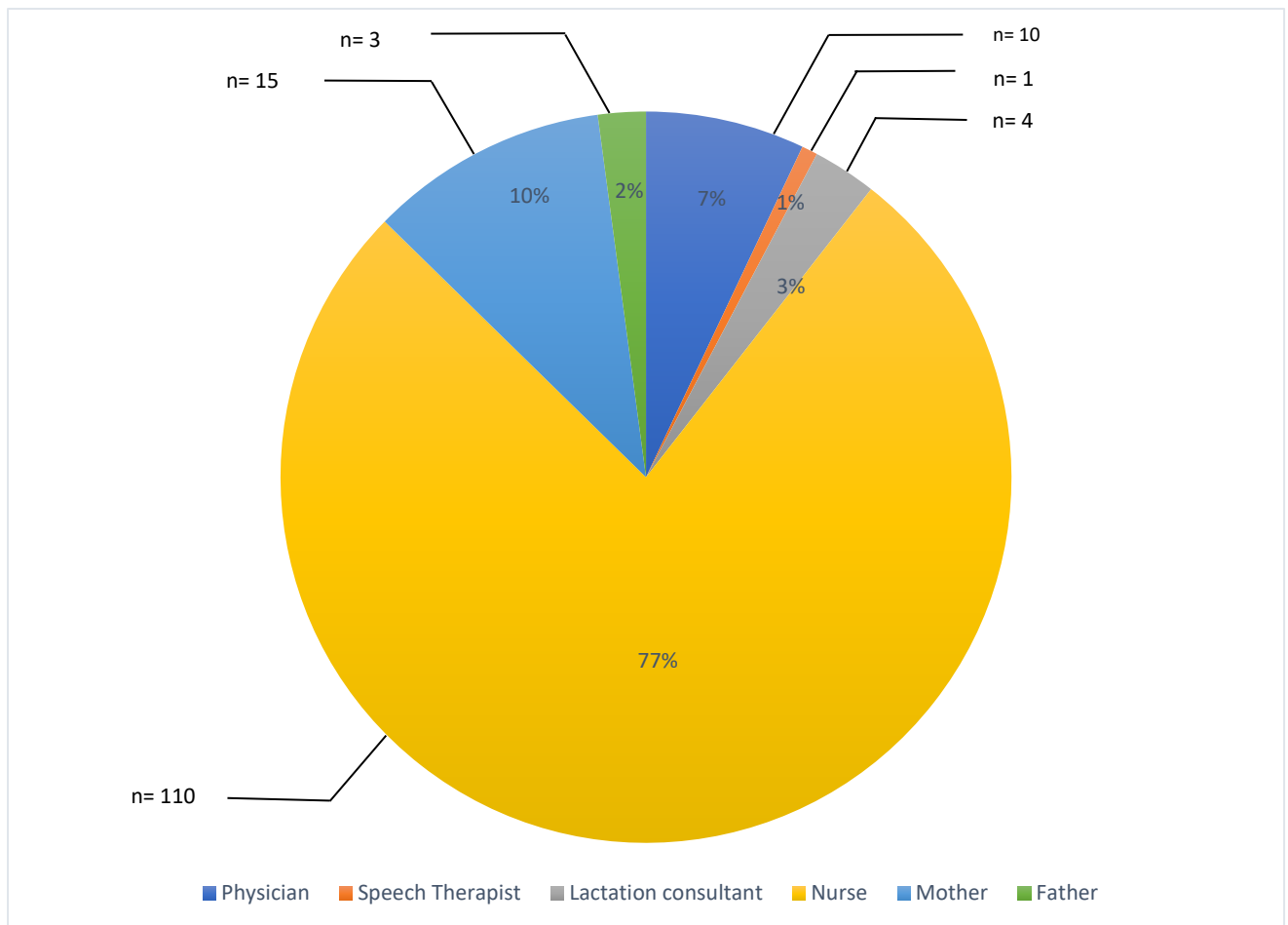
The two surveys were disseminated to targeted groups, with a total response of n=133 healthcare workers, and n=21 caregivers. The completion rate for the healthcare workers was n=69.92%, while the parents had a completion rate of n=71.42%.

According to the gatekeepers, more parents were recruited to take part in the study, though no record of their numbers is kept. This, in turn, means that the response rate cannot be calculated. The same applies to the medical staff as their numbers in each hospital was not obtained.

3.3 Participants

Of the healthcare worker group, n=129/133 consented to participate, but n=125 were included for analysis as they followed through the survey items pass the consent page. They comprised of physicians, an SLT, LCs, and nurses (Figure 3.1). The healthcare group had n=112 that worked in the NICU/SCBU, n=4 were stationed in the outpatient clinics, and n=7 worked in both places. The caregiver group had n=21 responses from mothers and fathers and n=1 did not consent (Figure 3.1). Those who stated that their baby still resides in the hospital were n=15, while n=3 were already discharged and may or may not be following up in outpatient clinics.

Figure 3.1 Percentages of all participants from both targeted groups



3.4 Level of awareness

There are four questions in both surveys pertaining to level of awareness of an SLT's profession. (Figure 3.2). Majority of the healthcare staff have heard of SLTs/Speech Language Pathologists (SLPs), while less than half of the caregivers know of the speciality's name.

Below half of the participants from both groups thought that SLTs work with all ages, while the remainder answered "neonates and infants", "paediatrics" and "adults" (Figure 3.3).

Most healthcare workers responded with *probably yes* to knowing what disorders an SLT works with, and a handful of them answered *definitely not*. The caregivers had n=50% of its participants respond with *probably yes* to question five, while the rest did not know what type of patients SLTs manage (Figure 3.4).

Due to an error in assigning the correct logic to question 11, it did not appear to the healthcare group until it was adjusted, which resulted in two responses. However, this question was shown to the caregiver group. A summary of the results can be found in Table 3.1.

Figure 3.2 Hearing of the profession's name

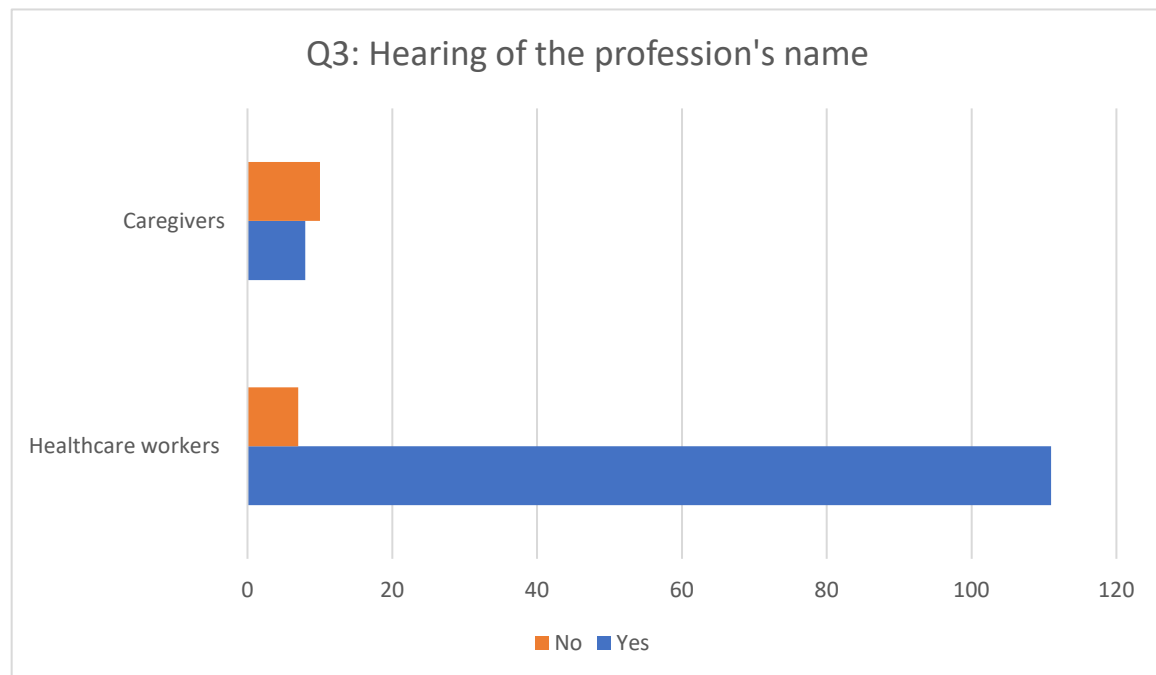


Figure 3.3 Age groups SLT's work with

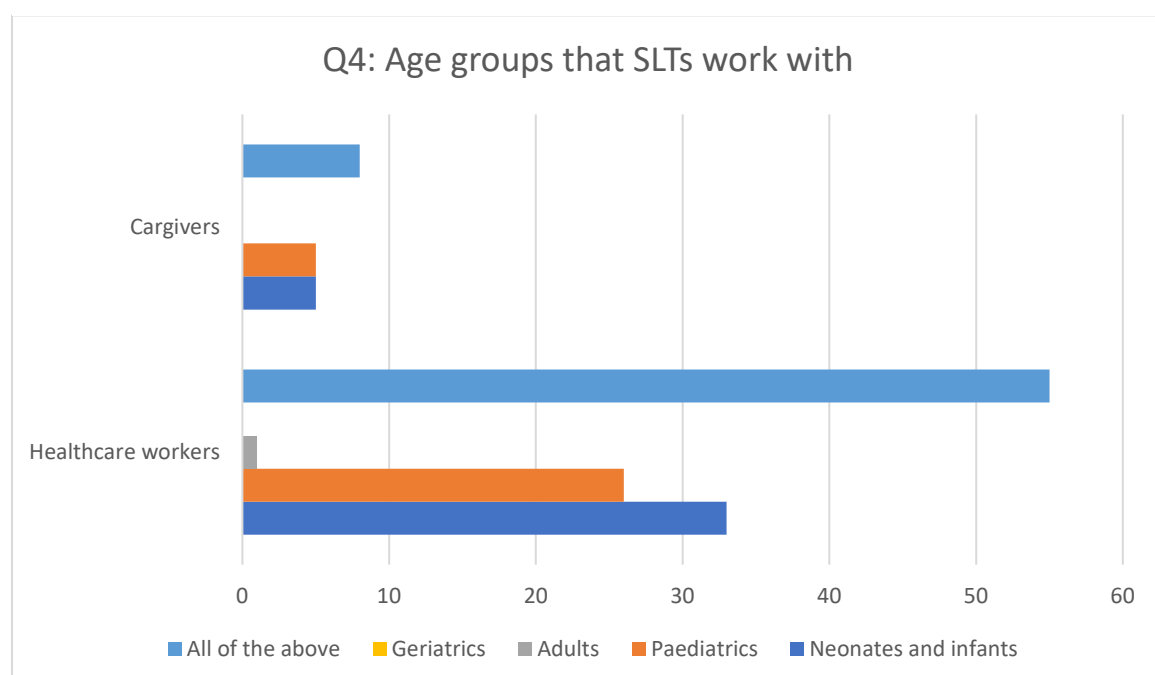


Figure 3.4 *Knowing what disorders SLTs work with*

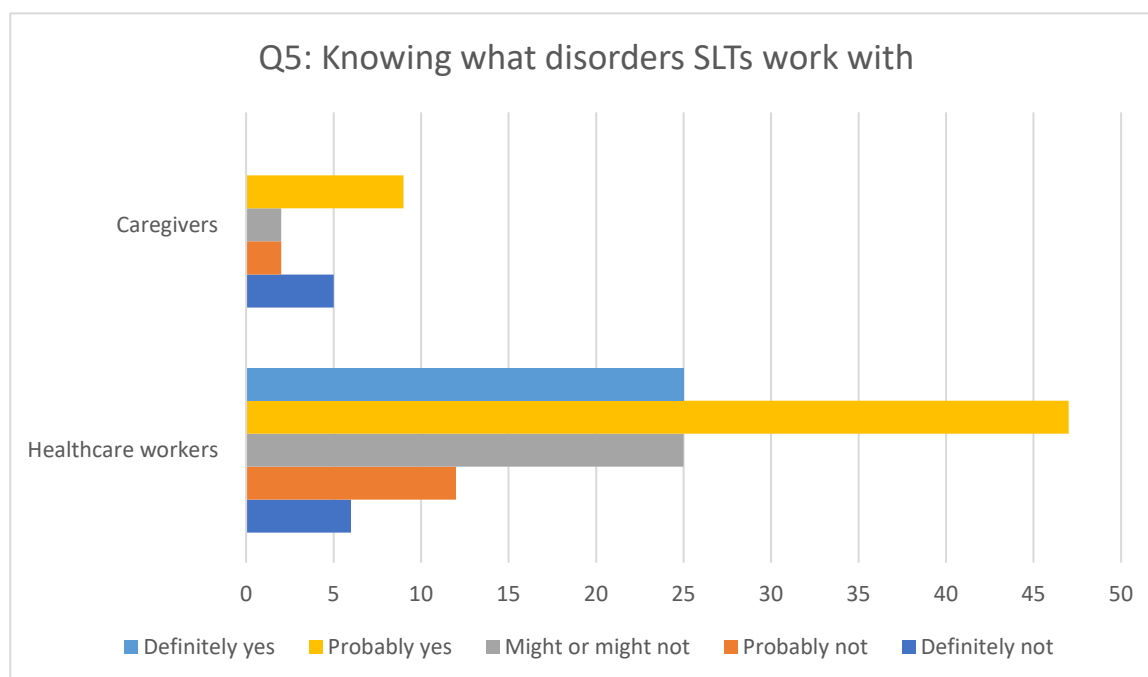


Table 3.1 *All participants' responses to questions 11 and 17*

Questions	Responses of the healthcare group		Responses of the Caregiver group	
	Answers	Count	Answers	Count
Healthcare group, Q11: What services do you think a Speech Therapist provides in the management of infants with swallowing and feeding issues?	General answer:	n = 1	General answers:	n = 6
	"Exercises"		- "Evaluate a baby"	
			- "Continues training"	
Caregiver group, Q17: How do you think a Speech Therapist can help your baby	Does not know:	n = 1	Does not know:	n = 8
	"I do not know"		"I do not know"	

swallow and feed safely?				
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3.5 Current practices in infant dysphagia management

The items that fall under this theme are questions 6, 7, 8, 9, 10, 11, 12, 13, and 14, with questions 15 and 16 relating to level of knowledge and comfort in managing and feeding infants with and without dysphagia (Table 3.2).

A total of n=113 healthcare staff who work in NICU/SCBU reported receiving referrals for infants with feeding and swallowing problems, and n=3 were not referred such cases (Figure 3.5). Those who work in outpatient clinics n= 7 stated that parents reported concerns of managing their infant's feeding and swallowing issues on average M=66.57% of the time (SD = 23.68). Regarding service provision, majority of healthcare workers would refer an infant with dysphagia to an SLT (n = 59), followed by assessing and treating them (n = 43), with referring to a PT being the least done (n = 31).

An outcome of interest is the healthcare staff's level of comfort and knowledge in assessing and treating infants with deglutition problems, and in counselling parents on managing their infant's feeding (Table 3.2). In addition to examining association between level of comfort and knowledge in each service type. Spearman's rho correlation analysis was done on three pairs of variables. The variables were level of comfort and knowledge in assessing infants' feeding and swallowing skills, level of comfort and knowledge in treating infants with feeding and swallowing difficulties, and level of comfort and knowledge in providing guidance to parents with infants who have swallowing and feeding problems (Table 3.2). There is a moderate positive association between level of comfort and knowledge in evaluation $r_s(131) = 0.644$, $p < 0.001$. Level of comfort and knowledge in both treating infants and guiding parents had a strong positive relationship, $r_s(131) = 0.763$, $p < 0.001$, and $r_s(131) = 0.721$, $p < 0.001$, respectively.

Figure 3.6 *Healthcare workers receiving referrals for infants with feeding and swallowing concerns*

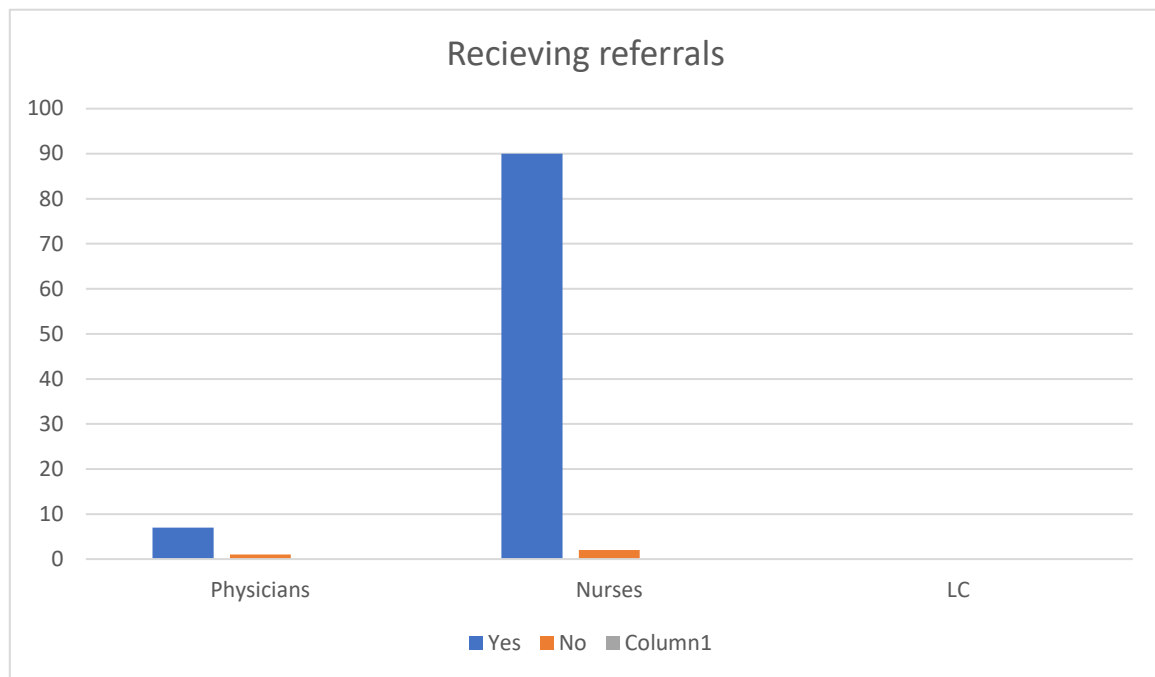


Table 3.2 *Healthcare workers' responses to questions 6, 7, 8, 9, and 10*

Questions	Multiple choices and scales	Physicians	Nurses	Lactation Consultants	All healthcare workers
Q7: How often do parents report concerns in managing their infant's feeding and swallowing issues post NICU/SCBU discharge? (0: being least, and 100: being most)	Scale	M = 68.50 SD = 29.29 Range: 18 - 89	M = 56 SD = 6 Range: 50 - 62	M = 65 SD = 15 Range: 50 - 80	M = 66.57 SD = 25.57 Range: 18 - 89
Q8: Which of the following services would you provide to parents with concerns of their infant's feeding and swallowing difficulties?	Counsel and advice the caregivers	n = 3	n = 32	n = 1	n = 36
	Provide assessment and treatment	n = 4	n = 37	n = 2	n = 43
	Refer to a Physical Therapist	n = 4	n = 27	n = 0	n = 31
	Refer to an Occupational Therapist	n = 6	n = 31	n = 1	n = 38
	Refer to a Speech Therapist	n = 3	n = 56	n = 0	n = 59
	Refer to a Lactation	n = 3	n = 29	n = 0	n = 32

	Consultant				
	Other	“All”	“Feeding exercises”		
Q9: How comfortable are you with each of the following (0: being least, and 100: being most)	Assessing infants with swallowing and feeding difficulties	M = 44.42 SD = 28.68 Range: 8 - 88	M = 74.01 SD = 24.50 Range: 0 - 100	M = 78 SD = 8 Range: 70 - 86	M = 72.11 SD = 2.73 Range: 0 - 100
	Treating infants with swallowing and feeding difficulties	M = 33.14 SD = 26.41 Range: 5 - 84	M = 72.83 SD = 24.20 Range: 0 - 100	M = 57 SD = 27 Range: 30 - 84	M = 69.86 SD = 2.83 Range: 0 - 100
	Providing guidance to parents with infants who have swallowing and feeding difficulties	M = 46.00 SD = 27.75 Range: 8 - 82	M = 73.18 SD = 24.43 Range: 0 - 100	M = 59 SD = 29 Range: 30 - 88	M = 72.14 SD = 2.65 Range: 0 - 100
Q10: How would you rate your level of knowledge in each of the following (0: being least, and 100: being most)	Assessing infants with swallowing and feeding difficulties	M = 49.28 SD = 23.93 Range: 5 - 78	M = 79.66 SD = 19.63 Range: 30 - 100	M = 59.00 SD = 29.00 Range: 30 - 88	M = 77.26 SD = 2.28 Range: 5 - 100

	Treating infants with swallowing and feeding difficulties	M = 39.42 SD = 24.65 Range: 5 - 86	M = 75.71 SD = 21.13 Range: 10 - 100	M = 54.50 SD = 25.50 Range: 29 - 80	M = 73.50 SD = 2.51 Range: 5 – 100
	Providing guidance to parents with infants who have swallowing and feeding difficulties	M = 64.85 SD = 22.37 Range: 20 - 92	M = 76.88 SD = 21.59 Range: 10 - 100	M = 55.50 SD = 25.50 Range: 30 - 81	M = 75.98 SD = 2.32 Range: 10 - 100

Parents who had infants with feeding and swallowing problems received guidance from LC, OT, and SLT, with the satisfaction level ranging from *extremely satisfied*, *somewhat satisfied*, to *somewhat dissatisfied*. There were four text inputs for question 13 regarding the type of guidance received. The responses encompassed feeding strategies and they were as follows:

“Flow change”

“Showing me how to deal with it”

“Visits twice a day to help my baby improve”

“Paying close attention during feeds, avoid force feeding the child when he is refusing, and ceasing feeds when observing stress signs”

Out of the six parents who completed question 14 about how they helped their infant who had feeding and swallowing issues, two have asked a physician, one consulted a PT, OT and LC, and three sought help from an SLT (Table 3.3).

There were 16 parents who answered question 15 pertaining to level of comfort on how the baby is fed, whether it is by them or another caregiver. Their answers ranged from *somewhat uncomfortable* to *extremely uncomfortable* (Table 3.3).

Table 3.3 *Caregivers' responses to questions 6, 7, 8, 9, 10, 11, 12, 13, 14, and 15*

Questions	Multiple choices and scales	Fathers	Mothers	All Caregivers
Q6: During your baby's NICU/SCBU stay, have you directly observed any feeding or swallowing difficulty?	Yes	n = 0	n = 5	n = 5
	No	n = 2	n = 7	n = 9
Q7: During your baby's NICU/SCBU stay, were you told by the medical staff of any feeding or swallowing difficulty?	Yes	n = 0	n = 5	n = 5
	No	n = 2	n = 7	n = 9
Q8: After your baby was discharged from the NICU/SCBU, have you observed any feeding or swallowing difficulty?	Yes	n = 0	n = 2	n = 2
	No	n = 0	n = 1	n = 1
Q9: Before your baby left the hospital, were you told by the medical staff to follow up in outpatient clinics due to your baby having feeding and swallowing difficulties?	Yes	n = 0	n = 2	n = 2
	No	n = 0	n = 1	n = 1
Q10: If your baby had feeding and swallowing difficulties, were you given any guidance on how to manage it?	Yes	n = 0	n = 6	n = 6
	No	n = 0	n = 2	n = 2

Q11: The person who gave you guidance on managing your baby's feeding and swallowing difficulties was a:	Doctor	n = 0	n = 0	n = 0
	Physical Therapist	n = 0	n = 0	n = 0
	Occupational Therapist	n = 0	n = 1	n = 1
	Speech Therapist	n = 0	n = 3	n = 3
	Lactation Consultant	n = 0	n = 1	n = 1
	Nurse	n = 0	n = 0	n = 0
	Professional from outside the hospital	n = 0	n = 0	n = 0
	Other	n = 0	n = 0	n = 0
Q12: How satisfied were you with the guidance given to you?	Extremely dissatisfied	n = 0	n = 0	n = 0
	Somewhat dissatisfied	n = 0	n = 1	n = 1
	Neither satisfied no dissatisfied	n = 0	n = 0	n = 0
	Somewhat satisfied	n = 0	n = 1	n = 1
	Extremely satisfied	n = 0	n = 3	n = 3
Q14: Which of the following have you done to help your baby who has feeding and swallowing difficulties?	Consulted/referred to a doctor	n = 0	n = 2	n = 2
	Consulted/referred to	n = 1	n = 0	n = 1

	a Physical Therapist			
	Consulted/referred to an Occupational Therapist	n = 1	n = 0	n = 1
	Consulted/referred to a Speech Therapist	n = 0	n = 3	n = 3
	Consulted/referred to Lactation Consultant	n = 0	n = 1	n = 1
Q15: How comfortable are you on how your baby is fed?	Extremely uncomfortable	n = 0	n = 1	n = 1
	Somewhat uncomfortable	n = 1	n = 0	n = 1
	Neither comfortable nor uncomfortable	n = 0	n = 0	n = 0
	Somewhat comfortable	n = 1	n = 8	n = 9
	Extremely comfortable	n = 0	n = 5	n = 5

3.6 Feedback on training program

The targeted groups were asked two questions of what they would like a training program to include and how would they want it delivered to parents in order to train and guide them on safe and efficient infant feeding.

A total of 89 healthcare workers and 14 caregivers completed the question about what they would want a training program to comprise of in the event one was to be developed. Of the 89 healthcare staff responses, one had no opinion. The remaining 88 inputs are described below. Content analysis was generated for both targeted groups and the following are the results:

3.6.1 Healthcare workers

The first common pattern found is parental involvement in the care of their infant, emphasizing on early education, teaching, and supporting parents. There was a total of n=20/88 responses that fall under this theme.

“Maintaining child health, improve parents’ confidence”

“Mental support”

“Participation of parents in early stage”

“Both parents & care takers involvement”

“Train mothers how to feed”

“Parents should be well aware of such difficulties in their infants. Early detection may ease their future hassle as proper feeding is very important for the infant and may lead to baby’s good health”

“Demonstrate how to feed the infant...teach them how to feed their baby and let the mother redemonstrate”

“Teaching parents”

“Parent counselling”

“Counselling parents of children with feeding difficulties”

The second observation, in which n=27/88 participants reported shared suggestions, is the provision of visual aids, videos, and demonstrations to further aid acquiring and maintaining what would be taught to the parents.

“Live demo”

“Demonstration”

“Videos”

“Demonstrate with bottle and pacifier”

“Some visual aids”

“Include demonstration”

The third noticeable theme is including feeding strategies and interventions, and ways to position infants during feeds. Of the 88 respondents, n=15 had similar responses.

“Feeding methods”

“Feeding exercise”

“Improve sucking and swallowing”

“Positioning”

“Feeding posture”

“How to hold the baby comfortable for feeding”

“Proper positioning during feeds”

“Feeding techniques”

“Positioning, burping, frequency”

Fourthly, there were n=8/88 comments on providing SLT services and guidance on breastfeeding.

“Speech and development”

“Breastfeeding education and speech therapy”

The fifth theme shared amongst n=7/88 inputs is the acknowledgement of the usefulness of a training program.

“Yes”

“The program is good for the babies”

“Can help both parents and staff to be satisfied of their job”

Theme number seven includes n=6/88 participant reporting to generally include such a training program in the care of infants.

“Health talk”

“Include in baby care”

“Follow up to be done”

The eighth perceived pattern is that some of the participants clearly promoted MDT involvement in infant care, while other replies are interpreted belonging to this theme. A total of n=5/88 remaining responses fit within this context.

“Include Baby Friendly Hospital Initiative (BFHI) team”

“Lactation team”

“Paediatrician, nurse, swallowing therapist”

“Speech and Occupational Therapists”

3.6.2 Caregivers

The majority of parents (n = 5) responded with “yes”, which may be an approval to create a training program. Further clarification will be provided in the discussion chapter.

Feeding techniques were the second observed theme (n = 3).

“How to know if I am feeding my child correctly and safely”

“Mentioning other ways to prepare the throat such as putting drops in the mouth”

“Knowing how to feed the child in a good and safe manner for him”

The third pattern seen is not having an input or not knowing what to comment (n = 4)

“I do not know”

“None”

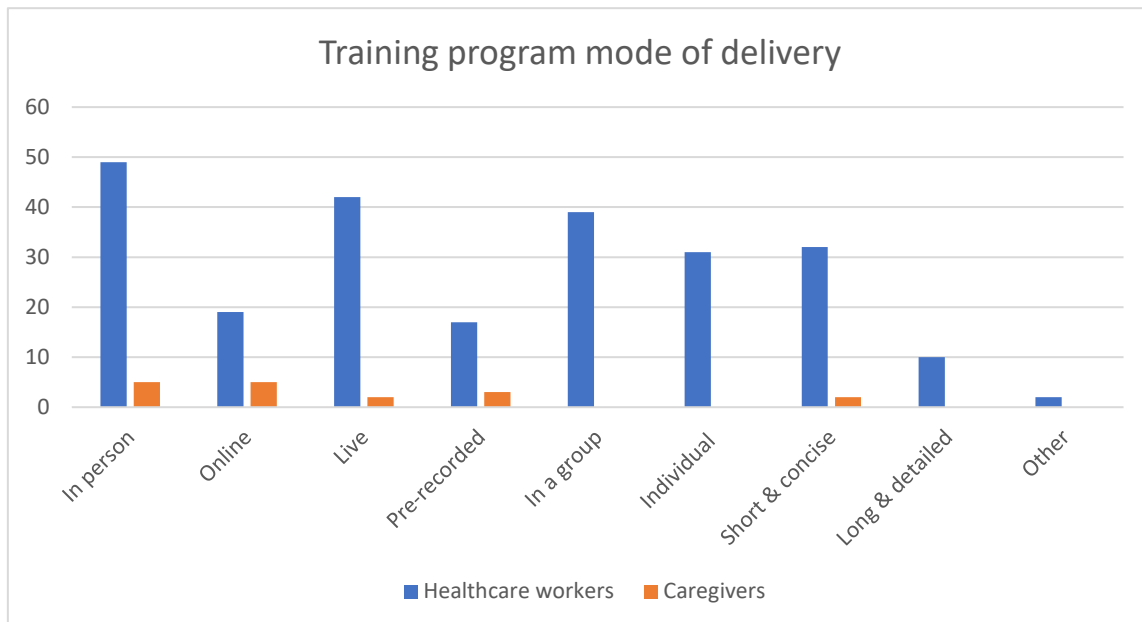
There was one participant who wanted guidance on breastfeeding, and another suggested including visual aids.

“How to breastfeed”

“Pictures and videos”

In terms of mode of delivery, the majority of both the medical staff and caregivers prefer it presented in-person. Healthcare workers want it done live rather than pre-recorded, and others would like it short and group-based. An equal number of parents who want a face-to-face training also chose online, slightly more would want it pre-recorded instead of live, and a few would prefer it to be short in duration (Figure 3.3).

Figure 3.5 Participants' responses to the last questions (Q13 in the healthcare survey, and Q17 in the caregiver survey)



Chapter 4: Discussion

4.1 Introduction

This study was aimed at identifying the level of awareness amongst the medical staff and caregivers in the NICU/SCBU and follow up clinics regarding the SLTs profession in general, as well as in managing infants with dysphagia in the State of Kuwait. It also looked at recent practices and services provided in these settings. Moreover, feedback from participants on the content and mode of delivery for a training program if one were to be made was acquired. This chapter discusses the results obtained, limitations, and future research directions.

4.2 Main findings and interpretation

4.2.1 Responses

An expectation from this study was to gain a representative sample size from the targeted groups, namely the caregivers since their feedback of the services are integral for improving performances. It is unclear what the reason might be for the small number of parents who participated, but it is thought that they may not have the capacity to even attend to their child, let alone complete a survey due to being a vulnerable population and that mothers are in postpartum stage. In addition to the high prevalence of IVF treatment (KUNA, 2019), this and other factors may increase fatigue and depression in mothers postpartum (Lee et al., 2011), which may be one of the explanations behind the low number of participants. Such conclusions stem from the principal investigator's clinical experiences and discussions with nurses who directly observe and interact with parents. Moreover, the Mental Capacity Act (2021) stated that mental illnesses are amongst the factors affecting the capacity to make decisions and provide customized approaches to vulnerable people applicable for research planning and research quality enhancement.

As for the number of respondents from the medical staff, some of the gatekeepers expressed being understaffed and overworked, therefore the addition of completing a survey might have posed as an inconvenience. Staff study burden was one of the outcomes addressed by Asch et al. (2000) via a systematic study of community-based physicians functioning as mediums for contacting other fellow medical members. They found that the targeted population were more willing to participate in a study when asked by a familiar physician. On the other hand, physicians felt uncomfortable to further burden the staff with extra tasks.

The results of this study heavily relate to nurses as they formed the majority of the participants.

In a study by Broyles et al. (2011) addressing facilitators and barriers to nurses' participation in focus group research, they recommended using a multimodal recruitment method that includes: reduced duration of focus groups while providing incentives, on-site recruitment, increased colleague to colleague recruitment at the nurses' convenience, awareness of the sensitivity nature of the research topic, and promote participant involvement in the research process. These recruitment approaches reflect the causes of low response rates that could also be related to other members of the healthcare workers.

4.2.2 Level of awareness

Most of the healthcare staff reported hearing of the profession SLT/SLP, but half of them had varied answers of what age groups and type of cases are handled by SLTs. The same applies to the caregiver group, except that half of them have heard of the profession, while the remainder have not. These findings are similar to Janes' et al. (2021) outcomes that revealed the public of Queensland, Australia have heard of the discipline's name, but do not demonstrate enough knowledge on the scope of practice. An observation noticed during the survey piloting stage with caregivers is that they referred to SLTs as LCs since a direct translation of LC from Arabic to English is "feeding consultant", which matches what SLTs practice in a NICU setting. Therefore, caregivers may be associating SLTs' profession with speech and language cases only without dysphagia management. This may explain the reason behind not knowing what an SLT does with infants especially that they "don't talk" as what is commonly heard by both parents and staff members based on the principal investigator's clinical experience. It may also account for the prevalence of older children having untreated FEDS problems. It is often reported by parents that they never knew of the profession's existence and the fact that dysphagia is assessed and treated by SLTs, alongside other disciplines. Furthermore, parents also expressed not being referred by a physician whom they would expect to have better knowledge on where to receive dysphagia management services. To the researcher's knowledge, no study has examined the patients' and physicians' confusion of the SLT's job title and scope of practice. However, the profession's name has indeed been a long debate with the aim of capturing the essences of what an SLT practices (Patterson, 2005; Robinson, 2010). Moreover, McHutchion et al. (2021) described dysphagia as an "invisible disorder" and that the lack of awareness amongst healthcare and non-

healthcare people could contribute to undiagnosed dysphagic cases and the undesired consequences of untreated deglutition issues.

The higher participation and level of awareness amongst the medical staff may be attributed to the fact that lectures were presented to hospital directors, physicians, and nurses from multiple hospitals about SLTs and their services. This can be seen in their feedbacks about designing a training program.

It was concluded from the inputs of all participants that they possessed no or limited information on the role of SLTs in the NICU/SCBU. Some have provided general and non-specific answers such as “exercises”, and others conveyed having no knowledge.

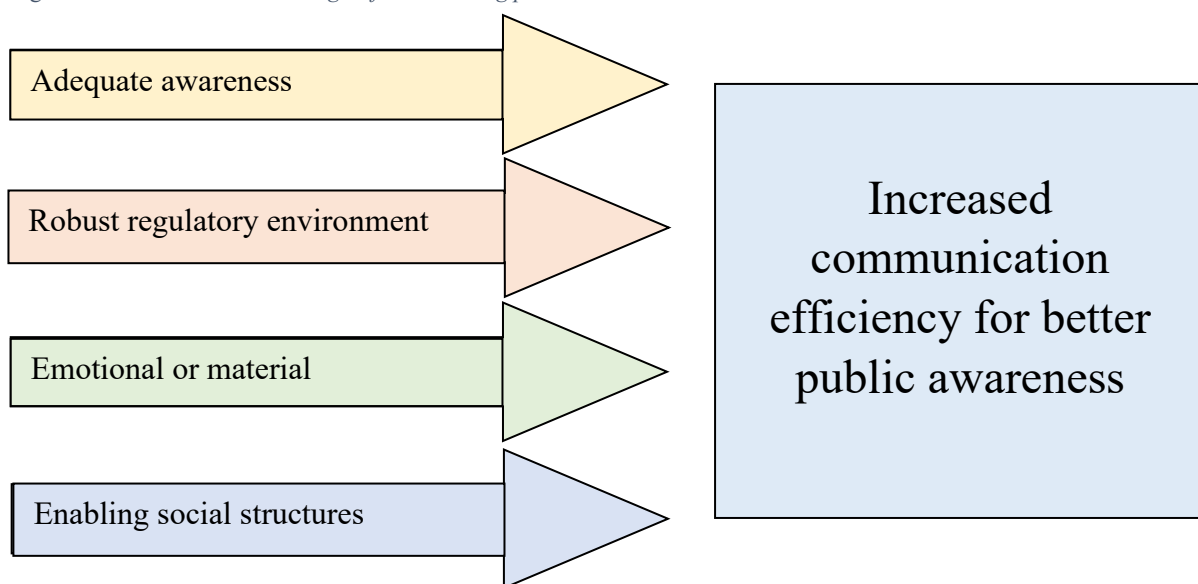
It is recognized that a larger sample size is needed to accurately determine level of awareness in the Kuwaiti population (Krejcie & Morgan, 1970), but it is evident from what was amassed that education to increase the understanding of SLTs’ profession in general and how they may aid in infant swallowing and feeding management is warranted, namely within the caregivers group. This is in accordance with the conclusions of other studies done in Kuwait regarding level of awareness, knowledge and attitudes of the public towards aphasia (Aljenai & Mackie, 2021) and stuttering (Al-Khaledi et al., 2011), in which they found that the population had poor knowledge of the disorders and the SLTs’ occupation. When comparing to other countries, Patterson’s et al. (2015) findings showed that the public of southern Ontario, Canada had limited understanding of aphasia. A study in Shanghai, China reported reduced knowledge on some areas concerning stuttering, but overall were familiar of various aspects of it (Ming et al., 2001). Another research was conducted with Turkish patients in a neurology unit (Mavis, 2007). It stated that an understanding of aphasia is low and that SLTs were one of the sources of information, therefore, the author advocated for SLTs and neurologist to cooperate and develop educational programs to improve public awareness. Public awareness of communication disorders and SLT in Malaysia was studied and revealed a positive trend towards it, while still lacking information in some areas of SLT services (Tang & Chu, 2021).

Since deglutition issues have detrimental effects on the health of infants and their caretakers (Arvedson, 2002; ASHA 2004; Goday, 2019; Senekki-Florent & Walshe 2021; Dunitz-Scheer, 2009; Obeidat et al., 2009) and negative sequelae resulting from missed diagnosis and intervention is highly likely to occur, actions such as awareness campaigns should be taken into consideration. Campaigns have been realized to undeniably increase public health

awareness, resulting in enhanced care performance such as reported by Seymour (2017) on palliative care. Other benefits encompass patient-empowerment that leads to better shared decision making, higher service quality, prevents disease sequelae, improves care safety, and increases healthcare accessibility (Alemu et al., 2021, Schildmeijer et al., 2018). Increased recognition may contribute to timely referrals and parent competency in handling their infants, thereby reducing workload on the staff, decreasing length of stay, and limiting resource consumption. Increased appropriate referrals was also observed in a study by Beucke et al. (2019) upon implementing The HealthySteps Effect for mothers with postpartum depression. The initiative amalgamated various specialist to aid in young children's positive development, providing guidance and behavioural health care. This program may be adapted to better the services in infant care in the Kuwait.

Mathew et al. (2019) have reported that merely raising the level of awareness will not necessarily create change in behaviour of stakeholders and suggested certain communication strategies that focus on delivering key messages rather than an influx of information provision. They proposed four pillars in which this process rests on and they are illustrated in Figure 4.1 below. Organizations such as the MOH would form credible channels to promote change and can be providers of material incentives and enforcers of regulations. Funding can be requested to set up online resources and provide necessary tools for forming a training program on infant care for both practitioners and service-consumers. Collaboration with public or private sectors is seen as one out of other key factors that aid in successful public health programs (Frieden, 2014).

Figure 4.1 *Communication strategies for increasing public awareness*



4.2.3 Current practices in infant dysphagia management

In order to improve intensive and special care services, along with follow up practices, it was vital to identify what is currently being done in the hospitals of Kuwait, who is responsible for infants' feeding and swallowing evaluation and intervention, in addition to how satisfied service consumers are.

More than half of the healthcare staff would receive referrals and reports of parents concerned of their infant's feeding and swallowing abilities. This showed the prevalence of such issues and the demand for experts to assist.

Most of the healthcare workers would refer an infant with feeding issues to an SLT, which was also seen in the caregiver group when asked what they have done to support their infant's feeding. Physicians, nurses, and LCs had providing assessment and treatment as their second or first option in infant care, which generally matched their levels of comfort and knowledge on these services. It can be argued that LCs are well trained on the matter and so are expected to have higher levels of knowledge. However, the same cannot be said for physicians and nurses since they do not undergo detailed training on infant feeding and swallowing management. Neonatologist are responsible for different aspects in infant care, for instance nutrition and metabolism. They do not, though, cover therapeutic strategies to support infant oral feeding or identify stress and readiness signs (Royal College of Physicians of Ireland, 2019). Few studies have addressed neonatal nurses' knowledge in infant oral feeding management. One study by Girgin & Gözen (2020) found that nurses working in a NICU needed more evidence-based information and practical skills on interventions facilitating oral feeding, cued-based feeding, safe feeding positions, and bottle feeding using slow-flow nipples. They also mentioned in another study of theirs that nurses required knowledge on NNS (Girgin et al., 2021). The least done was referring an infant to PTs. There could be more than one explanation such as the fact that they play other important roles in infant care, as well as the availability of therapists.

These outcomes showed the varied and inconsistent services and referrals done by different disciplines, as well as their knowledge on each speciality. Some physicians would refer an infant to an OT, nurses were more likely to request an SLT, and LCs would manage the infants on their own. Consequently, best practice services were likely not being implemented (NANT, n.d.; ASHA, n.d.; IASLT, 2021; Craig & Smith, 2020), then again, a large-scale

sample would have increased accuracy of the results, and so no solid conclusion of what is currently practiced can be made.

Regarding levels of knowledge and comfort in the healthcare workers, the two questions were phrased in a similar manner and it was realized later that perhaps emphasising the single difference with bold writing would have been helpful since one expressed confusion during the pilot stage. Consequently, the validity of these two questions in the staff survey is affected. The results showed moderate to strong association between the two variables in terms of assessing, treating, and counselling caregivers in the management of infants with dysphagia. In line with the Dunning-Krueger effect (Duignan, 2020), this was a counter-intuitive result. The theory describes people's tendencies to overestimate their abilities due to being unaware of the knowledge they still lack, meaning that such results are not necessarily predictable or follow common sense. To note, individuals' self-evaluation is affected by various factors and such tendencies do not necessarily apply to all and are subjected to alterations as the level of knowledge changes. A true estimation of one's capabilities may be achieved upon gaining enough knowledge and experiences. Social desirability is another factor influencing one's self-assessment of skills and is a natural, biased result of asking questions relating to it (Choi & Pak, 2005). It is assumed that if detailed questions about infants feeding assessment and intervention methods were asked, precise findings may be depicted such as what was done by McHutchion et al. (2021).

Deductions may include carrying out lectures to professionals about infant feeding and swallowing and how each play similar and dissimilar roles in different aspects of infant management, thereby improving performances, namely in infant neuroprotective care, as well as forming and promoting MDT. Additionally, nurses and LCs directly handle bottle and breastfeeding, thus hands on training for them and other specialities interested can be implemented for service quality control. Relvas et al. (2019) have studied the use of a complementary manual alongside training workshops for continuing staff education in a primary health care unit. Their results indicate that using the manual helped reduce inadequate supplementary feeding practices for infants. Developing written resources for staff members, thus, can be considered. Lectures and printed materials have been implemented on nurses in two hospitals of Kuwait, in which feeding strategies, as well as readiness and stress signs education was done. It was followed by an audit that showed 70% of nurses knew when to refer an infant to an SLT, 80% accurately identified feeding and distress signs during feeds, 70% demonstrated knowledge on preparations to do prior to

feeding like facilitated tuck and safe feeding positions, and 80% recognized faulty practices that impact an infant's feeding quality. It is evident from the outcomes that training was useful, but some have requested for live demonstrations and that matches their responses in this study of what they would want a training program for parents to contain. A protocol for nurse training on infant oral feeding techniques have been investigated by Touzet et al. (2016). The training was done on a period of 22 months by an expert MDT. They evaluated effectiveness of the program by infants reaching full oral feedings, measuring time needed for the transition, caregivers' theoretical and practical knowledge, and caretakers' satisfaction level with the training program. Their methods could be adapted in Kuwaiti hospitals and assessed in similar manner, since the previous lectures given were brief and did not involve an MDT or extensive interactive workshops. The difficulty anticipated is inadequate space and time to conduct the hands-on training. These would need to be discussed by other stakeholders to reach potential solutions.

4.2.4 Feedback on training program

As stated in chapter 1, an increase in workload and service quality was impacted by the large number of ART in Kuwait (KUNA, 2019) that consequently lead to increased LBW and preterm infants (Sunkara et al., 2015; Cavoretto, 2018; McDonald et al., 2009 & 2010). Finding a means to handle great numbers of infants and their families while maintaining quality and consistency is required; this is where the idea of developing a training program came from. The opinions shared by the health care workers reflect such needs.

The data obtained from the medical staff concerning the content of a training program focused on supporting, educating on infant feeding strategies and engaging parents in the care of their infant from an early stage, as well as providing hands on practices and demonstrations. It is indeed an important aspect and aim of a training program considering the benefits and importance of family-centred care as reported by other studies and guidelines (IASLT, 2021; NICE, 2021; Meisels, 2000). A patient's understanding of their role in healthcare plays a major part in enhancing quality of care (World Health Organization [WHO], 2018). The same can be said when viewing parenting in a NICU setting as an occupation and how it is affected by the environment, causing complexities in facilitating parental involvement (Gibbs et al., 2010). Patients and healthcare providers are both responsible for encouraging patient participation where possible (Schildmeijer et al., 2018). Liddy et al. (2015) have examined the effects of health coaching program on patients. They found that it raised patients' level of awareness regarding diabetes, promoted a sense of

responsibility for health decisions, and enhanced accessibility of health resources. It can be deduced that a training program would provide comparable benefits and ought to be incorporated in infant management practices.

It is understood in this study from some of the medical staff's suggestions to teach parents about breastfeeding and speech development. This was a valid point since HRI have higher chances of speech and language delays and it is within the scope of practice of an SLT to provide positive auditory exposure to enhance language acquisition, as well as facilitate and encourage breastfeeding (Pineda et al., 2019; Oliveira et al., 2019; IASLT, 2021; NANT, n.d.; NICE, 2019; NICE, 2017). Additionally, there were comments regarding the usefulness in creating a program and one mentioned that it will help satisfy both parents and healthcare providers in terms of service provision and job responsibilities. It was inferred from this statement that less duties will be assigned to the medical staff if parents were more involved and trained. The last theme seen in this group was to incorporate other professionals such as OTs and Baby Friendly Health Initiative team (BFHI), which is in agreement with best practice guidelines (Dow et al., 2017; IASLT, 2021; ASHA, n.d.; WHO & United Nations Children's Fund [UNICEF], 2020) as enhanced healthcare performance is achieved when collaboration amongst various professionals is done, as well as when each profession is aware and upholds their designated role.

There was less feedback from caregivers about the training program and it matched some of the themes found in the medical staff group. Generally stated, they wanted to be taught correct and safe methods of feeding their infants, include guidance on breastfeeding, and to provide visual aids when training. Other respondents did not have any input. The lack of feedback may be due to limited knowledge of how an SLT can help, what can actually be done to improve the infant's feeding skills, not being the primary caretakers who feed the child, and the fact that not all parents who completed the survey have a child with deglutition issues, thus they did not seek solutions or assistance. Possible ways to increase response rate is to specifically target caretakers who do have infants with feeding and swallowing difficulties and acquiring their opinions and suggestions.

All participants who answered the last question on the surveys preferred the training program to be given live, face-to-face, within a group of other parents, and to be short and concise. These considerations and others from the literature will be taken into account for future projects.

4.3 Limitations

The first drawback of this study includes limited sample size of each group that would need to be larger if a demand for service change on a national level is sought after. This means that the validity of the results is affected. Moreover, the participants from the healthcare staff may have been individuals who received lectures on the profession of SLTs and their role in the NICU, thereby resulting in good level of awareness of the speciality in general. Caution, therefore, is to be taken in data representability. Secondly, there were missing information due to using incorrect logic and the fact that the survey was not fully completed by all respondents. Thirdly, supplemental or a different data collection route via interviews or focus groups may have been useful to include or be chosen instead of surveys in order to yield richer outcomes. Online option may alleviate the issue of space in carrying out interviews or focus groups. Fourthly, the inclusion of questions that elicited pre-determined and prestige biased answers. Converting these questions to open-ended ones may have provided a better and diverse insight to the levels of knowledge and comfort of the healthcare workers in infant dysphagia management. A question such as “What would you do if you noticed an infant with feeding difficulties during the course of your care?” could have been asked. Open-ended questions, however, have the possibility of reducing response rate and requiring longer hours to decode (Reja et al., 2003).

4.4 Future research

It would be of value to gather a larger sample size, especially with the caregiver group as their input provide beneficial information to possibly improve current practices in the hospitals of Kuwait. Barriers and facilitators to research participation in the Kuwaiti community could be studied in order to grasp what religious, cultural, circumstantial and other factors would be influencers in ICU settings. Broyles et al. (2011) suggestion of a multimodal recruitment strategy can be implemented for possible greater response rates. A survey that includes more nuances of SLTs’ scope of practice, as well as dysphagia aetiology and services can be disseminated to accurately capture and explore the public’s knowledge. This could be done in conjunction with awareness campaigns and in intervals to measure differences and effectiveness of the campaigns. Systematic reviews may aid in finding best strategies to form awareness campaigns and training programs. Additionally, factors affecting higher degrees of knowledge and awareness may be incorporated. Future studies could delve deeper into parents’ and guardians’ perspectives and experiences on infant management services and what are their expectations and needs via interviews and/or focus groups with

other stakeholders of relevance. Another project of interest is developing a training program using the preliminary data gleaned from this research and from available literature, while integrating various disciplines and service consumers in the designing process.

Should a survey study be conducted, a Public and Patient Involvement event prior to study initiation or during the process could be considered, thereby providing opportunities for them to voice out their thoughts and opinions as well as creating a tailored research design and approach. Survey dissemination may be differed long after the parents' infant is discharged from the hospital so as to reduce any potential pressure. This, however, may subject their responses to recall-bias if asked about anything relating to the services received. Another alternative could be assessing mental capacities of the caretakers and whether they are capable or not to willingly join a research project (Mental Capacity Act, 2021). Such assessment can be of benefit to an overall individualized patient care as well.

4.5 Conclusions

This study provides an overview of various stakeholders' knowledge and perspectives towards SLTs and the management of infants with swallowing and feeding difficulties in the State of Kuwait. It reflects the limited level of awareness of healthcare practitioners and service consumers. The results identify to some degree current practices of different experts and provide insight to caregivers' experiences and actions, thereby contributing to a better understanding of the subject of interest. The possibility of designing a training program is positively met and should be considered in order to improve healthcare performances and patient health outcome. Future researches that remediate this study's drawbacks and enrich the literature are encouraged.

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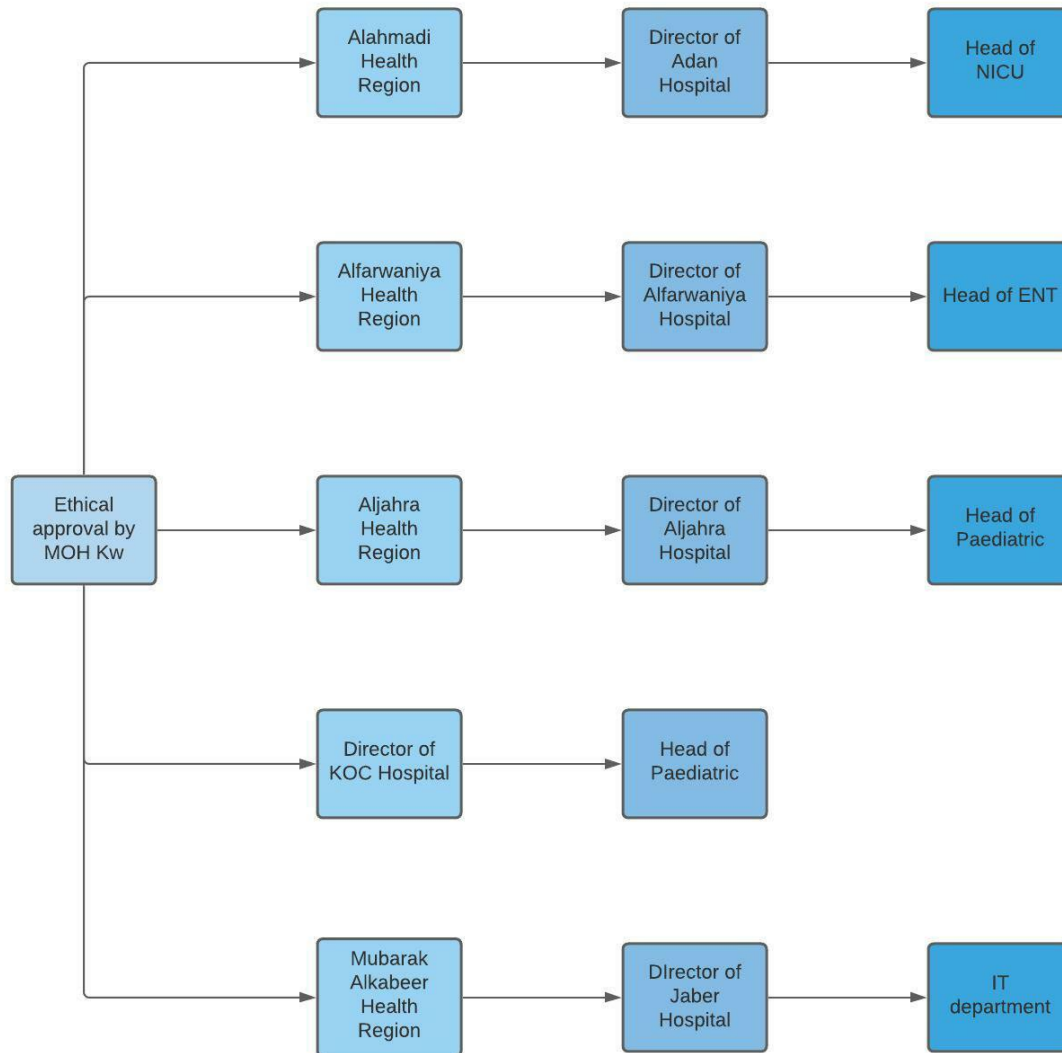
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Appendices

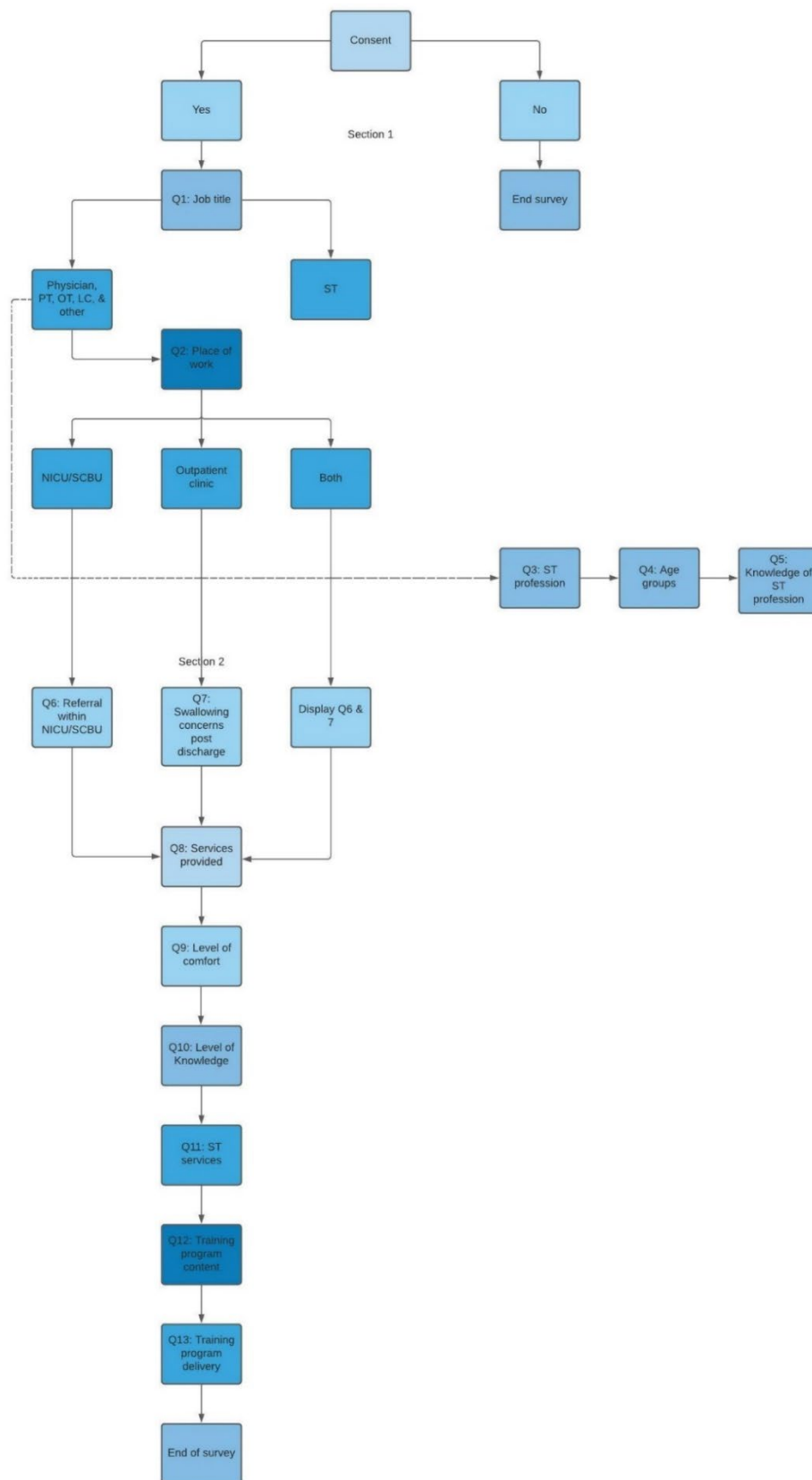
Appendix A

Ethical approval pathways, Kuwait



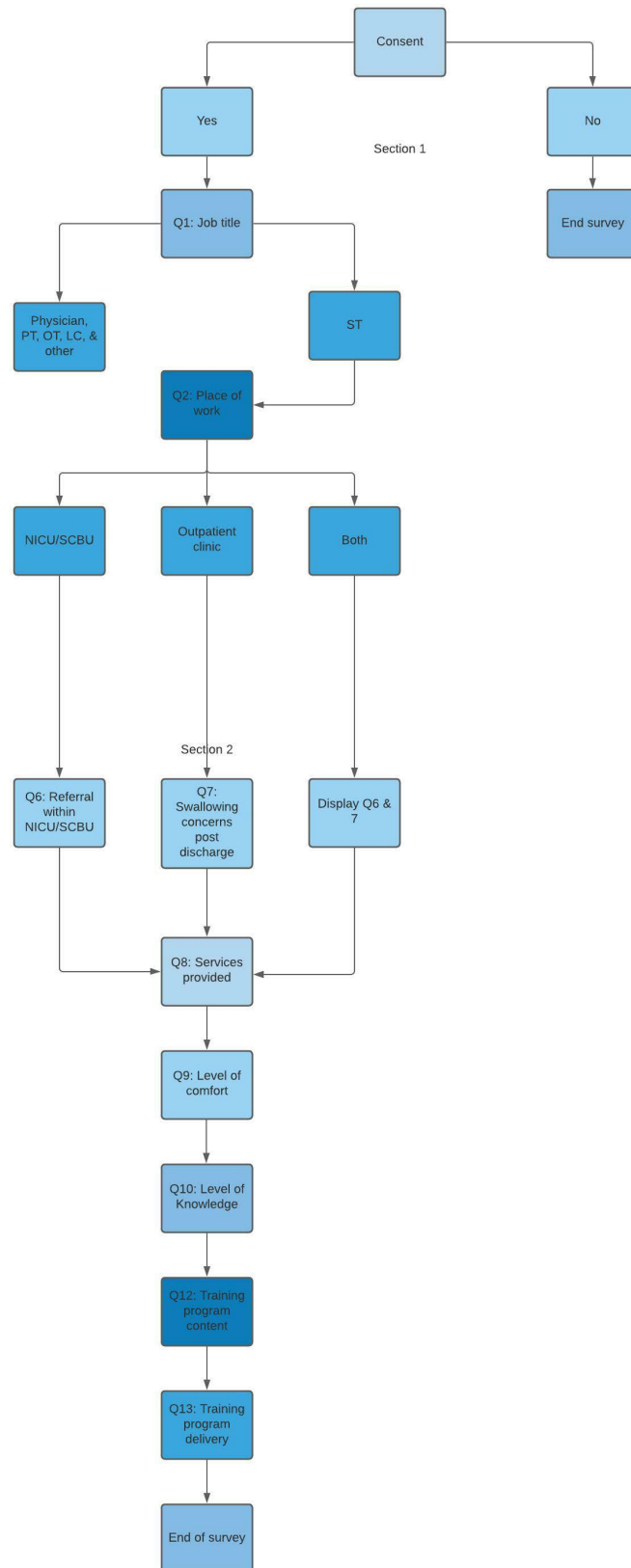
Appendix B

Medical staff survey: display and skip logic flowchart



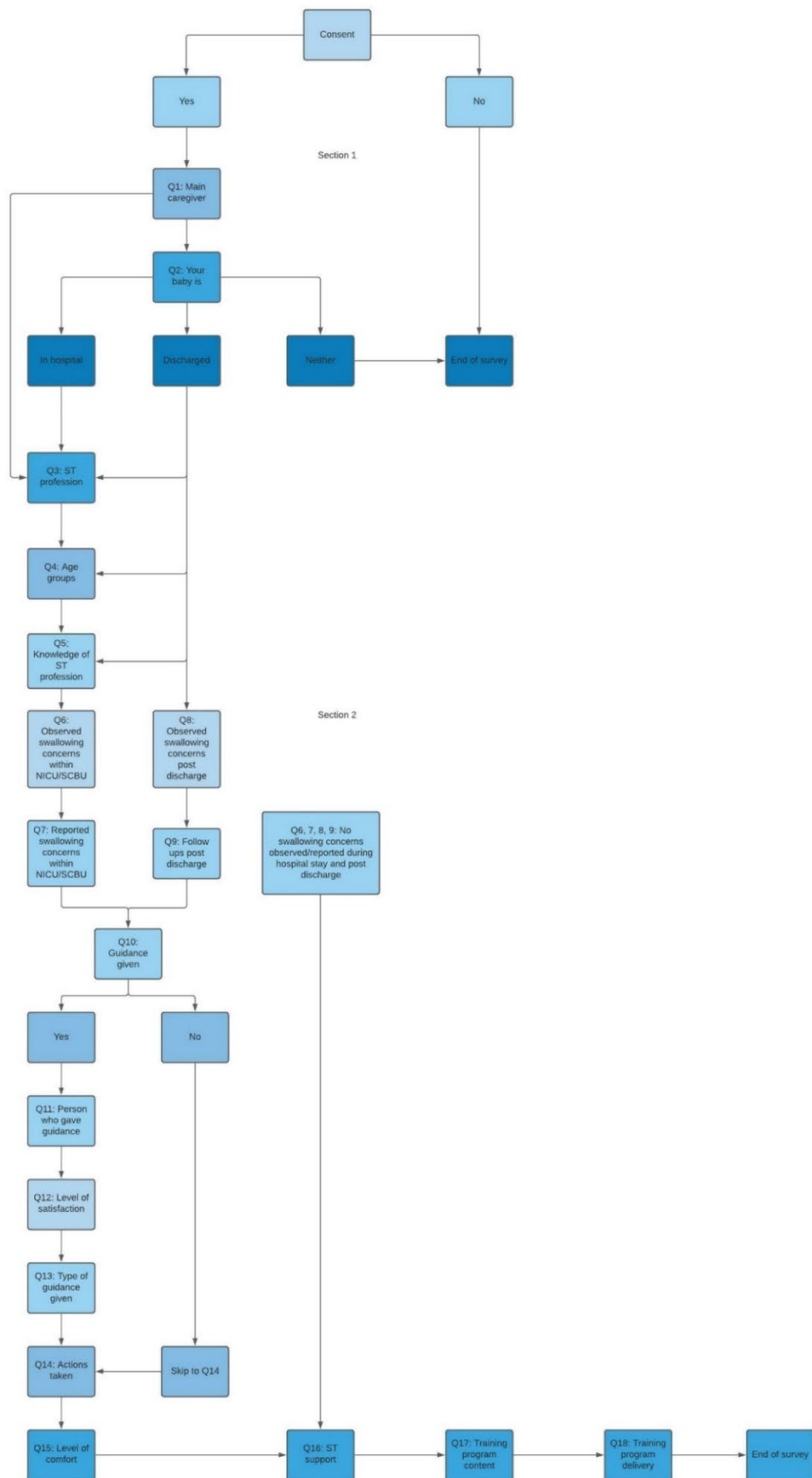
Appendix C

Medical staff survey (SLT): display and skip logic flowchart



Appendix D

Caregiver survey: display and skip logic flowchart



Appendix E

Ethical approval by the Ministry of Health Kuwait



State of Kuwait
Ministry of Health
Asst. Undersecretary
for Planning & Quality

دولة الكويت
وزارة الصحة
وكيل الوزارة المساعد لشئون
التخطيط والجودة



6318

المرجع :

To Whom it May Concern

28/12/2021 التاريخ :

From: Ministry of Health – Kuwait

The Standing Committee for Coordination of Medical Research

To: Fatemah Alquraini

UNIVERSITY OF Dublin – Trinity College

**Perspectives of Various Stakeholders Towards the Role of
Speech Therapists in the Management of Infants with
Swallowing and Feeding Difficulties**
(#1904/2021)

*The above mentioned Proposal was given an ethical approval
by the Committee on December 22, 2021.*

The research will be conducted in Kuwait MOH.

*Asst. Undersecretary for
Planning & Quality*

Head, Standing Committee for Coordination of Medical Research

Ministry of Health – State Of Kuwait

د. فاطمة عبدالمجيد محمد النجار
وكيل الوزارة المساعد لشئون التخطيط والجودة

Appendix F

Ethical approval from School of Linguistics, Speech and Communication Sciences



Trinity College Dublin

Coláiste na Tríonóide, Baile Átha Cliath

The University of Dublin

Application	Academic Year 2021/22
Applicant Code	HT34
Applicant/Supervisor Name	Fatemah Alquraini / Dr Ciarán Kenny
Title of Research	Perspectives on management of infants with FEDS
Date of this letter	15.02.22

Dear Fatemah,

Your submission for ethical approval for the research project above was considered by the Research Ethics Committee, School of Linguistic, Speech and Communication Sciences, Trinity College Dublin on 15/02/22 and has been approved in full.

Please note:

- (i) On completion of research projects, applicants should complete the *End of Project Report Form* (which can be found at: <https://www.tcd.ie/slscs/research/ethics/>) and submit one electronic copy (to slscs@tcd.ie)
- (ii) The REC requests, in particular, that you attend to your commitments regarding the storage and destruction of data arising from this research, in keeping with REC policy and General Data Protection Regulation (GDPR) guidelines.

We wish you every luck with your research.

Best wishes,

Dr Bronagh Ćatibušić

On behalf of:

Dr Ciarán Kenny

Chair, Research Ethics Committee

School of Linguistic, Speech and Communication Sciences

Appendix G

Caregiver electronic consent form/PIL

Purpose: You are invited to participate in a research study called: Perspectives of Various Stakeholders Towards the Role of Speech Therapists in the Management of Infants with Swallowing and Feeding Difficulties.

It is within the duties of a Speech Language Therapist to provide high quality services to their patients and the patients' family, especially premature babies who require intensive or special hospital care as they are susceptible to medical complications. It is, therefore, important to understand what are the current beliefs and management methods in Kuwait for babies with swallowing or feeding problems.

Participation: You can complete this survey if you are a mother, father, or guardian who has a baby staying in the hospital or a baby that is at home after being in the hospital in the State of Kuwait.

Instructions: This survey can be completed on either a mobile device or a computer within 10 minutes. Please ensure that you complete the survey once only and in one sitting.

Your rights and data: Participation in this study is completely voluntary and you may stop at any point. Any submitted response cannot be withdrawn and no personal information, such as your name and location, will be obtained. Your information will be handled by Trinity College Dublin.

Participation benefits: Participating in this study does not mean any additional service, such as assessment and treatment sessions for your baby, is to be given. Your participation, however, will help improve the overall services provided by Speech Therapists.

Ethical approval: This study has been approved by Research Ethics Committee of the School of Linguistic, Speech and Communication Sciences, Trinity College Dublin [code to be inserted upon ethical approval].

Contact for more information: This study is being

هدف البحث: أنت مدعو للمشاركة في البحث العلمي المسمى ب: انطباعات أفراد مختلفة تجاه دور أخصائي النطق واللغة في خدمة الأطفال حديثي الولادة والذين لديهم مشاكل في البلع والرضاعة. يعتبر تقديم خدمة عالية الجودة للمرضى وأهاليهم من ضمن مسؤوليات أخصائيي النطق خصوصاً للأطفال الخدج حديثي الولادة حيث أنهم من ضمن الفئة المعرضة لمشاكل طبية متنوعة ويترتب على ذلك معرفة ما يتم تقديمه في الكويت من خدمات وإرشادات لهذه الفئة وكذلك التعرف على مختلف الاعتقادات تجاه كيفية التعامل مع مشاكل البلع والرضاعة لدى الأطفال الخدج.

المشاركة في البحث: إذا أنت من دولة الكويت وكنت والد أو ولي أمر طفل يرقد ويتلقى العناية في المستشفى أو قد تلقى العناية من ذي قبل وهو الآن متواجد في البيت فيمكنك أن تجيب على هذا الاستبيان. **إرشادات:** يمكنك الولوج إلى الاستبيان عن طريق استعمال هاتف نقال أو الكمبيوتر حيث أن الاستبيان سيسغرق حوالي ١٠ دقائق لإكماله. يرجى الإجابة على الاستبيان مرة واحدة فقط وعدم ادخال الإجابات أكثر من مرة.

حقوق وبيانات المشارك في البحث: لديك كامل الصلاحية في الانسحاب من مشروع البحث في أي وقت تشاء حيث أن المشاركة غير إجبارية علماً أنه سيتم حفظ إجاباتك فور إدخالك إياها وسوف لن يتم الحصول على أي بيانات شخصية كاسم وموقع المشارك في هذا الاستبيان. بالإضافة أنه سيتم الحفاظ والتعامل مع المعلومات من قبل جامعة ترينيتي دبلن.

فوائد البحث: لا يوجد فوائد شخصية للمشارك في البحث كجلسات تقييم وعلاج إضافية للطفل وإنما تعود الفائدة لتحسين مستوى الخدمة المقدمة من قبل أخصائيي النطق.

التصريح لعمل البحث من قبل لجنة الأخلاقيات: لقد تم الحصول على الموافقة لعمل مشروع البحث من قبل لجنة الأخلاقيات التابعة لقسم علوم اللغويات والنطق والتواصل الواقع في جامعة ترينيتي دبلن.

التواصل: هذا البحث من عمل الطالبة فاطمة القريني وهو جزء من دراسة الماجستير تخصص اضطرابات النطق واللغة الإكلينيكي في جامعة ترينيتي دبلن الواقعة في دولة إيرلندا. يمكنك التواصل مع فاطمة عن طريق بريدها الإلكتروني alquraif@tcd.ie وكذلك التواصل مع مشرف البحث د.كيرن كني خلال بريده الإلكتروني

Ciaran.kenny@tcd.ie. بإمكانك التواصل مع dataprotection@tcd.ie إذا كان لديك أي استفسار عن حفظ وحماية البيانات الشخصية.

إقرار: أقر بأنني موافق على المشاركة في هذا البحث العلمي.

- نعم
- لا

conducted by Fatemah Alquraini as part of the MSc Clinical Speech and Language Studies in Trinity College Dublin. Fatemah can be contacted via email at alquraif@tcd.ie. The supervisor for this project is Dr Ciarán Kenny. Ciarán can be contacted at ciaran.kenny@tcd.ie. For questions or concerns regarding data protection: dataprotection@tcd.ie

Declaration: I consent to participating in this research study.

- Yes
- No

هدف البحث: أبت مدعو للمشاركة في البحث العلمي المسمى بـ: انطباعات أفراد مختلفة تجاه دور أخصائي النطق واللغة في خدمة الأطفال حديثي الولادة والذين لديهم مشاكل في البلع والرضاعة.

يعتبر تقديم خدمة عالية الجودة للمرضى وأهاليهم من ضمن مسؤوليات أخصائيي النطق خصوصاً للأطفال الخدج حديثي الولادة حيث أنهم من ضمن الفئة المعرضة لمشاكل طبية متنوعة ويترتب على ذلك معرفة ما يتم تقديمه في الكويت من خدمات وإرشادات لهذه الفئة وكذلك التعرف على مختلف الاعتقادات تجاه كيفية التعامل مع مشاكل البلع والرضاعة لدى الأطفال الخدج.

المشاركة في البحث: إذا أبت من دولة الكويت وكتب والد أو ولي أمر طفل يرقد ويتلقى العناية في المستشفى أو قد تلقى العناية من ذي قبل وهو الآن متواجد في البيت فيمكنك أن تجيب على هذا الاستبيان.

إرشادات: يمكنك الولوج إلى الاستبيان عن طريق استعمال هاتف نقال أو الكمبيوتر ومسح رمز الاستجابة السريعة أو كتابة الرابط في محرك بحث حيث أن الاستبيان سيستغرق حوالي ١٠ دقائق لإكماله. يرجى الإجابة على الاستبيان مرة واحدة فقط وعدم ادخال الإجابات أكثر من مرة. بإمكانك تغيير لغة الاستبيان عن طريق النقر على القائمة الموجودة في أعلى اليمين من الشاشة.



حقوق وبيانات المشارك في البحث: لديك كامل الصلاحية في الانسحاب من مشروع البحث في أي وقت تشاء حيث أن المشاركة غير إجبارية علماً أنه سيتم حفظ إجاباتك فور إدخالك إياها وسوف لن يتم الحصول على أي بيانات شخصية كاسم وموقع المشارك في هذا الاستبيان. بالإضافة أنه سيتم الحفاظ والتعامل مع المعلومات من قبل جامعة ترينيتي دبلن.

فوائد البحث: لا يوجد فوائد شخصية للمشارك في البحث كجلسات تقييم وعلاج إضافية للطفل وإنما تعود الفائدة لتحسين مستوى الخدمة المقدمة من قبل أخصائيي النطق.

التصريح لعمل البحث من قبل لجنة الأخلاقيات: لقد تم الحصول على الموافقة لعمل مشروع البحث من قبل لجنة الأخلاقيات التابعة لقسم علوم اللغويات والنطق والتواصل الواقع في جامعة ترينيتي دبلن.

التواصل: هذا البحث من عمل الطالبة فاطمة القريني وهو جزء من دراسة الماجستير تخصص اضطرابات النطق واللغة الإكلينيكي في جامعة ترينيتي دبلن الواقعة في دولة إيرلندا. يمكنك التواصل مع فاطمة عن طريق بريدها الإلكتروني alquraif@tcd.ie وكذلك التواصل مع مشرف البحث د. كيرن كني خلال بريده الإلكتروني Ciaran.kenny@tcd.ie. بإمكانك التواصل مع dataprotection@tcd.ie إذا كان لديك أي استفسار عن حفظ وحماية البيانات الشخصية.

رابط الاستبيان: <https://bit.ly/sltcaregiversurvey>



Note: Illustrated by Sarah Alquraini

Appendix I

Staff electronic consent form/PIL

Purpose: You are invited to participate in a research study called: Perspectives of Various Stakeholders Towards the Role of Speech Therapists in the Management of Infants with Swallowing and Feeding Difficulties.

It is within the scope of practice of a Speech Therapist to provide best practice services to patients and their families, namely infants in the Neonatal Intensive Care Unit (NICU)/Special Care Baby Unit (SCBU)/outpatient clinic, as they are a vulnerable group. It is, therefore, of value to identify current practices and beliefs in the management of infants with swallowing and feeding concerns.

Participation: You may participate if you are a physician, physical therapist, occupational therapist, speech and language therapist, lactation consultant or nurse working with infants in the NICU/SCBU/out-patient clinic in the State of Kuwait in one of the following hospitals: Adan, Maternity, Al-Jahra, Jaber, and Alahmadi (KOC).

Instructions: This survey can be completed on either a mobile device or a computer within 10 minutes, but it may take longer if you want to write more about your experience. Please ensure that you complete the survey once only and in one sitting.

Your rights and data: You do not have to participate in this study if you do not want to. It will not affect your career. It is completely voluntary and you may stop at any point. Any submitted response cannot be withdrawn and no information that identifies you will be obtained. The survey software (QualtricsXM) has been configured such that your IP address and geolocation are not captured. The data controller for this research is Trinity College Dublin.

Participation benefits: Please note that there is no personal benefit from participating in this study, however, your input will help improve the overall services provided by Speech Therapists.

Ethical approval: This study has been approved by Research Ethics Committee of the School of Linguistic, Speech and Communication Sciences, Trinity College Dublin [HT34].

Contact for more information: This study is being conducted by Fatemah Alquraini as part of the MSc Clinical Speech and Language Studies in Trinity College Dublin. Fatemah can be contacted via email at alquraif@tcd.ie. The supervisor for this project is Dr Ciarán Kenny. Ciarán can be contacted at ciaran.kenny@tcd.ie. For questions or concerns regarding data protection: dataprotection@tcd.ie

Declaration: I consent to participating in this research study.

- Yes
- No

Appendix J

Medical staff and caregiver surveys in English

Q No./ Groups	Staff	Caregivers
Section 1		
1.	Job title: - Physician: - Physical Therapist - Occupational Therapist - Speech Therapist - Lactation Consultant - Other (Please specify)	You are a: - Mother - Father - Guardian
2.	Do you work in: - NICU/SCBU - Outpatient clinic - Both	Is your baby: - Still in the hospital - At home after being in the hospital - Neither
3.	Have you ever heard of the profession “Speech Therapist/Pathologist”? - Yes - No	Have you ever heard of the profession “Speech Therapist”? - Yes - No
4.	Which of the following age groups is a Speech Therapist involved with? - Neonates and infants - Paediatrics - Adults - Geriatrics - All of the above	Which of the following ages do you think a Speech Therapist works with? - 0 – 2 - 3 – 14 - 15 – 60 - 60 + - All of the above
5.	Do you think you have good knowledge of what disorders a Speech Therapist works with? - Definitely not - Probably not - Might or might not - Probably yes - Definitely Yes	Do you think you have good knowledge of what patients a Speech Therapist works with? - Definitely not - Probably not - Might or might not - Probably yes - Definitely Yes
Section 2		
6.	In recent memory, have you received referrals for infants that have feeding or swallowing concerns and who are residing in the NICU/SCBU? - Yes - No	During your baby’s NICU/SCBU stay, have you directly observed any feeding or swallowing difficulty? - Yes - No
7.		During your baby’s NICU/SCBU stay, were you told by the medical staff of any feeding or swallowing difficulty?

		- Yes - No
8.	How often do parents report concerns in managing their infant's feeding and swallowing issues post NICU/SCBU discharge? - Slider	After your baby was discharged from the NICU/SCBU, have you observed any feeding or swallowing difficulty? - Yes - No
9.		Before your baby left the hospital, were you told by the medical staff to follow up in outpatient clinics due to your baby having swallowing and feeding difficulties? - Yes - No
10.		If your baby had feeding or swallowing difficulties, were you given any guidance on how to manage it? - Yes - No
11.		The person who gave you guidance on managing your baby's feeding and swallowing difficulties was a: - Doctor - Physical Therapist - Occupational Therapist - Speech Therapist - Lactation Consultant - Nurse - Professional from outside the hospital - Other (please specify): comment box
12.		How satisfied were you with the guidance given to you? - Extremely dissatisfied - Somewhat dissatisfied - Neither satisfied nor dissatisfied - Somewhat satisfied - Extremely satisfied
13.		What type of guidance were you given to help you manage your infant's swallowing and feeding difficulties? - Free text
14.	Which of the following services would you provide to parents with concerns of their infant's feeding and swallowing difficulties? - Counsel and advice the caregivers - Provide assessment and treatment - Refer to a Physical Therapist - Refer to an Occupational Therapist	Which of the following have you done to help your baby who has feeding and swallowing difficulties? - Asked a doctor for help - Asked a Physical Therapist for help - Asked an Occupational Therapist for

	- Refer to a Speech Therapist - Refer to a lactation consultant	help - Asked a Speech Therapist for help - Asked a lactation consultant for help - Other (please specify): comment box
15.	How comfortable are you with the each of the following (0: being least, 100: being most): - Assessing infants with swallowing and feeding difficulties (slider) - Treating infants with swallowing and feeding difficulties (slider) - Providing guidance to parents with infants who have swallowing and feeding difficulties (slider)	How comfortable are you on how your baby is fed? - Extremely uncomfortable - Somewhat uncomfortable - Neither comfortable nor uncomfortable - Somewhat comfortable - Extremely comfortable
16.	How would you rate your level of knowledge in each of the following (0: being least, 100: being most): - Assessing infants with swallowing and feeding difficulties (slider) - Treating infants with swallowing and feeding difficulties (slider) - Providing guidance to parents with infants who have swallowing and feeding difficulties (slider)	
17.	What services do you think a Speech Therapist provides in the management of infants with swallowing and feeding issues? - Free text	How do you think a Speech Therapist can help your baby swallow and feed safely? - Free text
18.	Imagine a training programme were developed to help teach parents how to safely feed their infants. What would be helpful to include in that programme? - Free text	Imagine a training programme were developed to help teach you how to safely feed your baby. What would be helpful to include in that programme? - Free text
19.	How do you think the training program should be delivered? - In person - Online - Live - Pre-recorded videos available online - In a group - Individual - Short and concise - Long and detail - Other (please specify): comment box	How do you think the training program should be delivered? - In person - Online - Live - Pre-recorded videos available online - In a group - Individual - Short and concise - Long and detail - Other (please specify): comment box

Appendix K
Caregiver survey in Arabic

Section 1
ما هي صلة قرابتك من الطفل؟ - أم - أب - ولي أمر
هل طفلك: - يرقد في المستشفى - متواجد في البيت بعد ما تلقى العناية في المستشفى - ليس أي مما ذكر
هل سمعت من قبل عن وظيفة تسمى "أخصائي نطق"؟ - نعم - لا
باعتقادك أي من الفئات العمرية التالية يتعامل معها أخصائي النطق؟ - ٠ - ٢ - ٣ - ١٤ - ١٥ - ٦٠ - ٦٠+ - كل ما سبق
هل تعتقد أن لديك معرفة جيدة بنوعية المرضى الذين يتعامل معهم أخصائي النطق؟ - بالطبع لا - على الأغلب لا - قد لا يكون - ربما نعم -
Section 2
هل لاحظت بشكل مباشر أن طفلك يعاني من صعوبات في الرضاعة أو البلع أثناء رقبوده في المستشفى؟ - نعم - لا
هل قام الطاقم الطبي بإبلاغك أن طفلك الذي يرقد في المستشفى يواجه صعوبات في الرضاعة أو البلع؟ - نعم - لا
هل لاحظت أن طفلك يعاني من أي صعوبات في الرضاعة أو البلع بعد خروجه من المستشفى؟ - نعم - لا
هل طلب منك من قبل الطاقم الطبي مراجعة المستشفى بعد خروج طفلك من العناية وذلك بسبب معاناته من صعوبات في الرضاعة أو البلع؟ - نعم - لا
هل تم إعطاؤك أي إرشادات عن كيفية التعامل مع طفلك الذي يواجه صعوبات في الرضاعة أو البلع؟ - نعم

- لا

تم إعطاؤك إرشادات عن كيفية التعامل مع طفلك الذي يواجه صعوبات في الرضاعة أو البلع من قبل: (اختر كل ما ينطبق)

- الطبيب
- أخصائي علاج طبيعي
- أخصائي علاج بالعمل
- أخصائي علاج النطق
- استشاري رضاعة
- الممرضة
- شخص متخصص من خارج المستشفى
- أخرى (يرجى التوضيح):

ما مدى رضاك من الإرشادات المقدمة لك؟

ما نوع الإرشادات التي تم تقديمها لك لمساعدتك في التعامل مع طفلك الذي يواجه صعوبات في الرضاعة أو البلع؟
أي من الأفعال التالية قمت به لمساعدة طفلك الذي يواجه صعوبات في الرضاعة أو البلع؟ (اختر كل ما ينطبق)

- راجعت طبيب
- راجعت أخصائي علاج طبيعي
- راجعت أخصائي علاج بالعمل
- راجعت أخصائي علاج النطق
- راجعت استشاري رضاعة
- أخرى (يرجى التوضيح)

ما مدى ارتياحك بالطريقة التي يتم فيها رضاعة طفلك من قبل الشخص المسؤول عن رضاعته؟

- غير مرتاح للغاية
- غير مرتاح إلى حد ما
- محايد
- مرتاح إلى حد ما
- مرتاح للغاية

باعتقادك كيف يمكن لأخصائي نطق أن يساعد طفلك على الرضاعة بشكل آمن؟

ماذا تريد أن يكون مضمون برنامج تم إنشاؤه لإرشادك عن كيفية رضاعة طفلك بشكل سليم وآمن؟

كيف تريد أن يتم التقديم أو العمل بالبرنامج؟ (اختر كل ما ينطبق)

- وجه لوجه
- عبر الانترنت (أونلاين)
- مباشر
- مسجل ومتوفر عبر الانترنت
- مع مجموعة من أولياء الأمور
- منفرد
- قصير ومختصر
- طويل ومفصل
- أخرى (يرجى التوضيح):

Appendix L

List of gatekeepers

Name & Qualification	Position & primary employer
Dr Anna John	Senior Neonatologist in Adan Hospital
Dr Ghanim Alghanim	Head of NICU in Jaber Hospital
Dr Munif Alhathal	Senior NICU Consultant
Dr Sulaiman Almunifi	Head of NICU in KOC Hospital
Dr Usama Shalabi	Head of paediatric department in Aljahra Hospital
SLP Hiba Alajmi	Speech Language pathologist in Adan Hospital
SLP Khaldah Alhamdan	Speech Language pathologist in Adan Hospital
SLP Mariam Alrubaian	Speech Language pathologist in KOC Hospital
SLP Reem Binzayed	Speech Language pathologist In PMR and Maternity Hospitals