



Investigation of the Effectiveness of an Ecologically Valid Telerehabilitation System for the
Assessment and Primary Management of Neurogenic Dysphagia in a Resource Constrained
Country

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**A dissertation submitted to the Discipline of Speech Language Pathology in the
School of Health Sciences in partial fulfilment of the requirements for the
Doctor of Philosophy in Speech Language Pathology
University of Kwa-Zulu Natal**

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November 2017

Declaration by the Researcher

I, Sona Ayanikalath, declare that the work that is presented in this thesis is original. I was responsible for the conceptual development, data collection, analysis and write-up of the thesis and the journal articles. My supervisors, Mershen Pillay and M. Jayaram, assisted with guidance and input during the process as necessary.

S. Ayanikalath

November 2017

Acknowledgements

My PhD became a reality with the support of a many special people who have stood by me through this phase. It is my pleasure to acknowledge them.

Mershen Pillay- the main pillar and my supervisor

You have never ceased to amaze me with your knowledge, dedication and hard work. Never in my wildest of dreams did I think that we would collaborate for a Ph.D., when I met you for the first time on 30th October 2007. You guided me into the world of dysphagia, which I was wary of. I realise that you had faith in me then and even today! Thank you, which is an understatement, for your unwavering support and motivation to do what was a herculean task! Thank you for being you- a guide I could laugh with, fight with, cry to, without any fear. I hope there is a long way to go for me and you- in the path of dysphagia!

Jayaram Sir- my co-supervisor

A genius with the kindest heart, which I realised when I started my Ph.D. Without you, nothing of this would have happened, especially the data collection and during the final stages of my Ph.D. My deepest gratitude for all the support and motivation you have provided.

Mr Rangasayee

Thank you, sir, for your support, motivation and prompt help at the right times.

Carrin Martin- the critical thinker and editor

Thank you for all the thinking you did, which I could not do; for all the time, you spent reading my work and your prompt feedback. Your knowledge and skills were invaluable

Dr Wilbert Sibanda

I am grateful for the valuable input and support you provided with my statistical analysis.

Dr Jaishen Rajah and Dr Virendra Kumar Mishra

Thank you for being kind and to show patience to listen to me and provide valuable suggestions during the final stages of my Ph.D.

Girish and Appu

Thank you would be an understatement, considering you have borne with my mood swings and aloofness from 'home-work' for the last 4 years. Girish- thank you for never doubting my abilities when I started and went through this! You have shown immeasurable patience, love, support, and constant encouragement throughout this Ph.D. and for everything we have done in life! And Appu- I can now finally be with you for everything!

Achan, Amma and Syama

With my thesis, I hope I will finally be fulfilling your long-standing dream of having a Ph.D. holder in your family. Thank you for making me always dream high and having faith in all the steps I have taken. Thank you for showing me the path of speech language pathology. I hope I will be a good example for Syama. Also, thank you Syama, for motivating me and for being obedient to do all the proof reading! Thank you for always being there for me.

Nuzha

We started this adventure named Ph.D. together and we have gone through the ups and downs together. Thank you for giving me a shoulder to cry on and laughing with me. Nobody

except you have understood my struggles the best way. I know we will be there for each other, always!

Farhana Khan and Maneesh Chandran

Thank you for all the valuable advice you provided during the ‘research proposal’ times.

Mathew George

Thank you for the constant support by giving me the books, even when I asked for them in the last minute.

My participants

My sincere appreciation to all the participants of this study for your support, input and precious time.

Thank you, GOD!

My pranamam to You, for showing me the light in every decision and step that I took in life. I never thought I was intellectually capable of doing a Ph.D. But You showed me otherwise! You made me take this path of Ph.D. on a day when I was feeling down; to thus show me that life always has its ups and downs. You made me see the positive side of every happening in life and thus redirected my energy and thoughts towards Ph.D. Thank you for all the blessings in my life!

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Abstract

India is undergoing remarkable industrialisation, economic and demographic changes resulting in a transition towards lifestyle related cardiovascular and cerebrovascular diseases and TBI. There is an increased number of individuals living with different physical, cognitive or affective sequelae of CVA and TBI. It leaves patients with several residual disabilities like physical dependence, communication impairment and dysphagia. Given the knowledge that CVA and TBI patients presenting with dysphagia are at a risk for pneumonia, there is even more need to manage dysphagia to prevent subsequent pneumonia.

Intervention of dysphagia is scarcely available in resource constrained countries due to various reasons. There is a dearth of dysphagia experienced speech language pathologists in India due to the wide geographic range and increasing population. In such cases, when there is a shortage of trained staff in underserved areas, a feasible solution may be to adopt TR. This is in light that TR is an emerging novel method and various studies are being conducted using TR for speech language pathology services.

TR studies on management of dysphagia have been conducted in economically developed countries like USA, Australia, etc. and mostly in controlled settings. Reports on impact of application of TR for management of dysphagia in resource constrained countries are almost absent. Ecological validity i.e. can results obtained under controlled research setting be generalised to those obtained in real life settings, and effectiveness, i.e. is it successful in producing desired outcome in dysphagia assessment, need to be assessed when considering developing a TR for use in India for the intervention of dysphagia, hence trying to investigate if the studies conducted successfully in the economically advanced countries be replicated in India.

Hence the researcher deemed it necessary to conduct the current study with the aim to investigate the effectiveness of an ecologically valid TR system for the assessment and primary management of neurogenic dysphagia in India. The current thesis is a series of three phases. The first phase (Chapter 2) aimed to explore the current literature available regarding the use of TR in the intervention of dysphagia using a narrative literature review. The objectives were to investigate the current status and feasibility of TR in the assessment and/or management of dysphagia and to identify the benefits and limitations of the studies to explain ecological validity of TR. The narrative literature review aided the researcher to identify that TR is a feasible method for the intervention of dysphagia in economically developed countries. It emphasized the gap in knowledge on the use of TR for the intervention of dysphagia in resource constrained country as there are no studies reported. Hence, the researcher identified that the literature review augmented her idea that ecological validity of TR needed to be identified and thus its effectiveness when implementing it in resource constrained countries, because the patient, clinician, technology and context related factors do play a major role. The identified factors were explored in greater detail in phase two, to ensure that the TR implementation for the intervention of neurogenic dysphagia is contextually responsive and holistic, based on the paradigm shift to a constructivist one, ontologically, epistemologically and methodologically.

The second phase (Chapter 4) aimed to investigate the ecological validity of TR in a resource constrained country such as India. Its objectives were to investigate the current status of TR in India through an understanding of the knowledge and attitude of TR personnel and to identify the variables that affect the ecological validity of TR in India based on the practice of the TR personnel. The semi structured interviews of TR personnel in India aided

the researcher to acknowledge that patient, clinician, technology and context related factors can affect the ecological validity of TR in a resource constrained country, which in turn will affect its effectiveness. However, tele-mode service delivery in India is a feasible proposition, and in fact, several institutions have successfully implemented it. TR and TR for the intervention of dysphagia can be an answer to the needs of people in the underserved areas in India.

With the outcomes from this phase, as well as based on the conceptual framework developed in phase one, factors such as devices and technology used for TR, the current internet speed available in the study location, materials used for the CSE and real-life outpatient clinical settings were used to establish the ecological validity of TR. Its effectiveness was then investigated. The third phase subsequently aimed to investigate the effectiveness of an ecologically valid TR for the assessment and primary management of neurogenic dysphagia in India. The objectives were to compare the results obtained using CSE through an ecologically valid TR mode and face-to-face mode with the intention to identify if the scores are reliable and to examine and explain the possible effects of the ecological validity variables i.e. patient, clinician, technology and context related factors on the effectiveness of TR in dysphagia assessment. Simulated patients (SP) were used for this phase, which was to avoid any harm to real patients (if used). This can be considered as a main limitation of the study.

The quantitative data analysis using percent exact agreement and Cohen's Kappa scores to rate the inter-rater reliability between the TR-SLP and FTF-SLP, showed that TR was effective in conducting neurogenic dysphagia assessment and primary management. There were high inter-rater reliability in all the cases studied. A descriptive analysis of the

results obtained could explain the reason for the variation in scores on certain parameters of the CSE in each case, in relation to the factors affecting the ecological validity. This qualitative descriptive analysis could explain how the various factors could have influenced the performance of the patient and clinician. However, due the small sample size of four SP in study two, the findings cannot be generalised to broader clinical settings. However, there is no denial that the results provide valuable preliminary information for future research of TR in resource constrained country.

The findings of the overall study identified the need for treating a new intervention as unique, developing in relation to a complex and potentially unique set of ecological conditions. The researcher identified the need for using a contextually guided framework when developing interventions such as TR, which in turn can improve its effectiveness. The results obtained from the current study feed motivation for future studies using real patients, first to be done in a controlled setting to reduce the risk of the consequences due to aspiration or choking during the assessment. The results of the current study will help and be an inspiration in future large-scale studies in resource constrained country and is food for thought for those already using TR for speech language therapy services in such settings.

Chapter One

Introduction

Advancement in communication technology has also brought advancements in the healthcare sector, mainly in the form of telemedicine (Hersh, et. al, 2006). Telerehabilitation (TR), which is a branch under the umbrella term telemedicine, has been defined as the delivery of rehabilitation services (i.e. assessment, monitoring, intervention, supervision, education, consultation and counselling) (Brennan, Tindall, Theodoros, Brown, Campbell & Christiana, 2011) via information technologies. TR, a system to provide rehabilitation services using information and communication technology (Russell, 2007), has also been used in the field of speech language pathology for the intervention of various speech, language and swallowing disorders.

The primary focus of the study was to investigate the effectiveness of an ecologically valid TR system for the assessment and primary management of neurogenic dysphagia in a resource constrained country. Primary management which includes diagnosis and primary treatment of neurogenic dysphagia including diet modification and follow up plan was carried out. This is in the light of the growing population with neurological disorders especially cerebrovascular accident and traumatic brain injury in resource constrained countries, with swallowing disorder, also known as dysphagia, being a main symptom of these disorders (Olszewski, 2006). TR is also relevant to resource constrained countries such as India because of the dearth of dysphagia experienced speech-language pathologists (SLP). India is resource constrained in health care field due to uneven distribution of healthcare providers (WHO, 2007),

low doctor to patient ratio (India has one government doctor for every 11528 people and one nurse for every 483 people) (Bagcchi, 2015) and poor working condition of public health facilities (lack of basic infrastructure and supplies) (WHO, 2007).

1.1. Background for the study

The main concepts of interest to the researcher were TR for dysphagia management, its ecological validity and its effectiveness in the management of neurogenic dysphagia management.

1.1.1. Neurogenic dysphagia due to cerebrovascular accident and traumatic brain injury.

Neurogenic dysphagia is a problem with swallowing ability that may be caused by a disruption in different parts of the central nervous system or neuromuscular and muscular disorders. Neuromuscular disorders causes can be cerebro-vascular accident (CVA) and traumatic brain injury (Olszewski, 2006). Cerebro vascular accident (CVA) happens when the blood flow to a part or parts of the brain is stopped either by a blockage or a rupture of a blood vessel. CVA is the second leading cause of death and a major cause of disability worldwide (Donnan, Fisher, Macleod, & Davis, 2008). Two thirds of CVA deaths occur in developing countries. Per reports, the incidence and 30-day case fatality rates due to CVA are higher in resource constrained countries than in developed countries (Dalal et. al, 2008) because of demographic and epidemiological transitions (Ghosal et. al, 2014). Dysphagia is a common

complication following TBI, with an incidence as high as 93 % in patients admitted to brain injury rehabilitation (Hansen, Engberg & Larsen, 2008). Dysphagia following traumatic brain injury (TBI) can be multifactorial, but mainly occurs because of neurological impairment to any or all the three phases of swallowing (the oral preparatory, the oral and pharyngeal phases) and cognitive-communication and behavioral dysfunction (Winstein, 1983; Cherney & Halper, 1989; Cherney & Halper, 1996; Morgan & Mackay, 1999).

In comparison with the industrialized economically developed countries where there has been a decline in CVA over the past 30 years, resource constrained countries India is currently facing the challenge of a high CVA incidence (Banerjee & Das, 2016). India with more than one billion inhabitants is undergoing remarkable economic and demographic changes resulting in a transition from poverty related infectious and nutritional deficiency diseases toward lifestyle related cardiovascular and cerebrovascular diseases. Driven by increasing size and escalating prevalence of risk factors such as hypertension, tobacco use, unhealthy diet, physical inactivity, and obesity, CVA is becoming a major cause of premature death and disability in developing countries like India. In 2002, it was estimated that nearly 1.5 to 2 million persons are injured and 1 million succumb to death every year in India (Gururaj, 2002). The burden of TBI is increasing every year due to rapid increase in motorization, industrialization and urbanization (Munivenkatappa & Agrawal, 2016).

There is limited availability of organized CVA and TBI care services to most people in such countries (Sridharan et. al, 2009). Very little reliable information is currently available regarding epidemiology of CVA in India (Sridharan et. al, 2009). The reported frequency,

pattern, risk factors and outcome of CVA from India are largely derived from hospital based observations. Conversely, advances in diagnosis and management of acute CVA have also improved survival in hospital settings, resulting in an increased number of individuals living with different physical, cognitive or affective sequelae of CVA (Hofgren, Björkdahl, Esbjörnsson, & Stibrant-Sunnerhagen, 2007) and TBI (Khan, Baguley & Cameron, 2003; Nicholl & LaFrance, 2009). It leaves patients with several residual disabilities like physical dependence, communication impairment and dysphagia (Mishra & Khaldilkar, 2010).

A major side effect of CVA and TBI is dysphagia, also known as neurogenic dysphagia. It is highly prevalent following CVA with estimates between 30-65%. Studies have found a high incidence of complications after CVA, ranging from 40% to 90% (Pandian & Sudhan, 2013). In India, a study showed that 22.3% of posterior circulation stroke patients develop dysphagia (Gupta & Banerjee, 2014). Compared with post CVA survivors whose recovery is not complicated by pneumonia, there is a threefold increased risk of dying when diagnosed with pneumonia after an acute CVA (Hinchey et. al, 2005).

Approximately one third of patients with dysphagia develop pneumonia requiring treatment (Hinchey et. al, 2005). Given the knowledge that CVA and TBI patients presenting with dysphagia are at a risk for pneumonia, there is even more need to manage dysphagia to prevent subsequent pneumonia. However, appropriate screening methods to identify those at risk for pneumonia in CVA survivors, and its subsequent management, have not been identified (Hinchey et. al, 2005). Almost 50% of patients with dysphagia experience aspiration.

Ickenstein et. al (2012) reported that 60% of patients with acute CVA who have dysphagia have associated silent aspiration, which leads to increased morbidity and mortality. Patients with dysphagia mostly present the symptoms within the first 5 days of hospitalization, leading to a six-fold increase in risk of aspiration pneumonia and a threefold increase in mortality. Pneumonia after CVA is usually associated with presence of laryngotracheal aspiration, 2-25% of which are concomitant with silent aspiration (Ribeiro et. al, 2015). Dysphagia can lead to malnutrition and may also lead to aspiration pneumonia, which in turn may even lead to mortality (Schindler, Ginocchio & Ruoppolo, 2008).

Among inpatient TBI patients in rehabilitation, the incidence of impaired oral feeding reportedly ranges between 25% to 93% [Winstein, 1983; Field, 1989; Mackay, Morgan & Bernstein, 1999; Terre & Mearin, 2007; Hansen, Larsen & Engberg, 2008]. In particular, 37% of severe TBI patients are unable to recover to an unrestricted diet after 18 weeks of inpatient rehabilitation (Hansen, Engberg & Larsen, 2008). Since dysphagia after brain injury can lead to malnutrition, dehydration, and aspiration pneumonia, adequate management of dysphagia is an essential part of TBI rehabilitation.

There is evidence that early detection of dysphagia can reduce or even prevent such complications as pneumonia, reduce length of hospital stay and overall healthcare expenditure (Martino et. al, 2005). The goals of dysphagia management should be to reduce these issues and thus improve the quality of life of the patients with neurogenic dysphagia. Thus, oral feeding ability in all patients with neurological disorders should be formally evaluated and managed to reduce risk of aspiration pneumonia and thus reduce length of stay in the hospital (Hinchey et al.,

2005; Terre, 2007). This can be done by a speech language pathologist (SLP) who will intervene to prevent aspiration by using diet modifications, postural changes and/or dysphagia therapy exercises (Hinchey et. al, 2005).

1.1.2. Role of SLP in the intervention of neurogenic dysphagia

Prevention of the negative health outcomes due to neurogenic dysphagia requires early identification and treatment. The SLP, as part of a multidisciplinary team, holds the primary responsibility for selection of an effective dysphagia rehabilitation program for these patients (Rogus-Pulia & Robbins, 2013). SLP plays a significant role in the screening, formal assessment, management, and rehabilitation of CVA and TBI survivors who present with dysphagia and/or communication impairment. Early diagnosis and referral is critical, as is intensive intervention as soon as the patient can participate. The SLP is also responsible for educating care givers and staff in strategies that can support the patient and for making appropriate environmental modifications (e.g. altering diet consistencies or providing information in an aphasia friendly format) to optimize the CVA or TBI survivor's participation, initially, in the rehabilitation program and, subsequently, within the community (Dilworth, 2008).

Evidence based practice for dysphagia management as per American Speech and Hearing Association recommends a detailed analysis of swallowing function at bedside and is called a clinical swallow evaluation. This can be followed by objective studies like videoflouroscopic study of swallow or fiber optic endoscopic evaluation of swallowing if required (Radhakrishnan, Menon & Anandakuttan, 2013). Studies such as that reported by Riberio et. al (2015) have

highlighted the importance of an objective examination in identifying specific changes in swallowing function, such as laryngeal penetration and laryngotracheal penetration. Treatment is to be followed with any of the three main strategies based on the characteristics of the swallowing impairment- compensatory management with diet modifications, postural changes and swallow manoeuvres; or provision of alternate nutrition; or swallow rehabilitation using different exercises for the oropharyngeal structures (Sura, Madhavan, Carnaby, & Crary, 2012) based on the characteristics of the swallowing impairment.

The intervention of dysphagia is scarcely available in resource constrained countries due to various reasons such as geographical (the vastness of the country and unpredictable weather changes), social factors (poverty leading to patients not accessing the medical services) and political factors (not having good medical services in some parts of the country due to differences in development and income). Physical access to medical services is a major concern in India (Patil, Somasundaram & Goyal, 2002). Imbalanced resource allocation, limited physical access to quality healthcare services, inadequate human resources, high out-of-pocket health expenditure and behavioural factors are some of the main factors that have posed a challenge to equity in health care service delivery in India (Balarajan, Selvaraj & Subramanian, 2011). Delivery of services for dysphagia management is also affected by these factors.

Even though dysphagia management is a part of the scope of practice of speech language pathologists (SLP) as per the American Speech and Hearing Association guidelines, in India, dysphagia is mostly managed by Ear, Nose and Throat doctors or neurologists, who do endoscopic evaluations as part of assessment of dysphagia and treat it pharmaceutically (Sarkar,

Sikdar & Kundu, 2012). Mostly it is the medical pathology like the CVA or the traumatic brain injury that is treated and thus indirectly reducing dysphagia (Sarkar et. al, 2012). There is a dearth of dysphagia experienced speech language pathologists in India due to the wide geographic range and increasing population. As per the 2015 list, the number of speech language pathologists and/or audiologists registered with Indian Speech and Hearing Association is 2500 (Indian Speech and Hearing Association, 2015).

This figure does not necessarily indicate the actual number of persons working as SLPs in India and the brain drain with many of the SLPs migrating to foreign countries for work (Suryanarayan & Madhoomita, 2008). The magnitude of brain drain among students' of speech and hearing graduates is 48% according to a survey in the year 2006 (Shah & Gore, 2016). Thus, the actual number of SLPs available in India is lesser than the number of them registered with ISHA (Suryanarayan & Madhoomita, 2008). Further, SLPs experienced in dysphagia management is even lesser when compared to the number of SLPs in India. Patient access to dysphagia experienced SLPs in India is fewer just like other allied health services (Suryanarayan & Madhoomita, 2008). Practising SLP prefer to opt for specialised practice in conditions such as voice disorders, child and language disorders and speech disorders (Shah & Gore, 2016). If a dysphagia experienced SLP is available, the logistics in terms of distance to travel, time taken and availability of an accompanying person pose problems.

It is a well-known fact that India has an extremely rich food culture in terms of food consistency variations. Indians have various soft foods such as idlis, dosas, kichdis and other rice items. With the researcher's experience, it has been observed that caregivers of patients with

dysphagia, usually feed the patient with soft food options. However, this is without proper diagnosis and intervention plan. Thus, the role of a dysphagia experienced SLP is deemed necessary.

Considering the mismatch between the demand and availability (Shah & Gore, 2016), particularly the availability of man power, there is a need to look for alternate methods of providing care to the underserved population. According to Zampolini et. al (2008) has a rich potential as a means of providing care for people in remote areas. TR has been adopted in India for providing care in many areas of health delivery (Ref ? ?). India would be an appropriate country to study the effectiveness of TR in the management of dysphagia considering the strides that it has taken in the field of computers, automation, communication technology etc. in the last 4-5 decades.

1.1.3. TR and its use for the intervention of dysphagia

There are studies on TR in the field of physiotherapy, occupational therapy, nursing and speech language pathology and they were mostly done in developed countries such as USA or Australia. In the field of physiotherapy, studies done by Russell, Blumke, Richardson and Truter (2010) and Chumbler et. al (2012) have shown that TR is a valid and reliable method means to provide physiotherapy intervention. Similar results have been reported in various studies done in the field of occupational therapy. Some studies to quote are those done by Schein, Schmeler, Holm, Saptono and Brienza (2010) and Barlow, Liu and Sekulic (2009). From the results of the various studies using TR in the different fields, it is noted that TR can be a reliable and valid tool

for the respective intervention. Many studies have been done and are still being conducted in the field of speech language pathology.

However, these studies specified the challenges or drawbacks faced during TR. Russel et. al (2010) reported that the online examiners reported difficulty in teaching participants to accurately perform and report the outcomes of specific orthopaedic tests. A potential solution to this problem could be to have a trained assistant present to conduct certain tests and guide movements under the instruction and guidance of the remote examiner. Chumbler et. al (2012) reported that they were unaware about extra challenges that can be present in applying the TR intervention to stroke survivors with receptive aphasia or other cognitive deficits. Some of the challenges related to the implementation of this intervention pertained to variable infrastructure of technology in the home (eg, availability of high-speed internet), issues pertaining to information security when using the internet for telecommunication, and technological needs for accurate real-time tele-video imaging of movement. Use of a store and forward technology could be a solution for this issue. Patient related issues such residual speech, language and cognitive deficits are also challenges.

The use of TR in the management of dysphagia is still in its early stages. There is limited evidence to support the utilization of TR in the management of dysphagia (Sharma, Ward, Burn, Theodoros & Russell, 2011). TR studies on management of dysphagia have been conducted in economically developed countries like USA, Australia, etc. and mostly in controlled settings. Reports on impact of application of TR for management of dysphagia in resource constrained countries are almost absent. In a country like India with its diverse landmass, huge population

and shortage of dysphagia experienced SLP; TR can be used to link the health care providers with a SLP at a distance. It can improve the quality and accessibility of care by allowing the SLP at a distant location to evaluate, diagnose, treat and provide follow up care to patients. This can help to improve the quality of life of patients and to achieve the goal of health for all in terms of dysphagia management for patients with adult neurogenic dysphagia.

1.1.4 Ecological validity of the TR system in the intervention of neurogenic dysphagia

Based on the knowledge from previous studies done using TR in the assessment and/or management of dysphagia the following doubts arose as to whether the study settings provide similar results in a real life setting, can similar settings be used across any country and whether the results of previous studies ecologically valid. Hence, the concept of ecological validity needed to be explored.

The word ecological validity came to light when the environmental context of research in the field of psychology and the impact the setting had on the study was questioned by Brunswick (1943) and Lewin (1943) (Schmuckler, 2001). The argument of ecological validity was handled when psychologists expressed their dissatisfaction with the limitations of laboratory experiments that did not appreciate the processes normally occurring in people's everyday lives. This dissatisfaction was expressed as long ago as 1930, by Dewey, and in 1932, by Bartlett. In 1947, Brunswick introduced the term 'ecological validity' to justify the opposition of representative

design (i.e., ecological approach in current terminology) to systematic design (i.e., traditional approach).

Brunswick suggested that psychologists shift their unit of analysis from people to the situations of the investigation and replace proper sampling of participants with a representative sampling of situations or tasks. Bronfenbrenner's (1977, 1979) classic definition of ecological validity is the extent to which the environment experienced by the subjects in a scientific investigation has the properties it is supposed or assumed to have by the experimenter (Schmuckler, 2001). As per Perkins, Florin, Rich, Wandersman and Chavis (1990), the concept of ecological validity refers most narrowly to the degree to which the definition of a unit of analysis reflects the way that unit is defined in real life by people or natural features.

Tupper and Cicerone (1990) explained ecological validity as the degree to which the results obtained in a controlled research setting can be generalised to those obtained in real life settings. However, validity does not apply to the test itself, but to the inferences that are inferred from the study (Franzen and Arnett, 1997). Cheytor and Schmitter-Edgecombe in 2003 provided a comprehensive review of the research on ecological validity of neuropsychological tests and identified that many of the tests have a moderate level of ecological validity when predicting everyday cognitive functioning. They also identified that some of the factors that may influence the ecological validity were the effects of the population being studied, the approach used, the clinician themselves, severity of the illness and time from the injury until evaluation. Hence, ecological validity has been extensively explored in the field of neuropsychology.

Crist (2015) described ecological validity in the field of occupational therapy, as the degree to which an assessment of events, activities or environments reflects real life expectations. The main goal of intervention in occupational therapy is to apply it to real life roles in natural contexts. Similarly, research on the intervention of dysphagia using TR should be to apply it in natural contexts. As such, ecological validity is a form of external validity. When external validity refers to the overall extent to which findings generalize across people, places and time, ecological validity refers more specifically to the extent to which findings generalize to the settings and people common today (Roy & Kathleen, 2007). In general, ecological validity is comprised of two different, but closely related aspects which are representativeness and generalizability. Representativeness refers to the naturalness of the situation and generalizability addresses the query if the findings of a study hold under real life circumstances (Kvavilashvili & Ellis, 2004).

To obtain results that are ecologically valid, the participants must be studied in the richness of their natural settings. Considering that previous studies on the use of TR for the assessment and/management of dysphagia have been done in economically advanced countries and specifically only for their geopolitical areas, ecological validity needs to be assessed when considering developing a TR for use in India, hence trying to investigate if the studies conducted successfully in the economically advanced countries be replicated in India. They have been frequently decontextualized.

Thus, there is an understanding that ecological validity has the potential to ensure that the professional philosophy in any field, including TR is comprehended in the daily lives of the

respective population. When considering the use of TR for the intervention of dysphagia in real life settings, there may be various factors that could possibly affect its ecological validity, which could be in terms of power and internet connection, poor literacy of patients and their caregivers, unavailability of computers or mobiles to provide TR services, etc. These factors hence, needed to be identified before implementing a new service like TR for the intervention of dysphagia in India.

1.1.5 Effectiveness of the ecologically valid TR system in the intervention of neurogenic dysphagia

Even though telemedicine, has been in use in India for more than a decade (Sinha, Tiwari & Kataria, 2012; Mishra, Kapoor & Singh, 2009), only a few studies have been reported on the use of TR (Rao, Iyer and Anap, 2012) who reported on the treatment of osteoarthritis knee through TR. There seems to be no study on the use of TR in the assessment and/or management of dysphagia reported in India.

It is recognized that the many factors that influence the ecological validity of TR for the intervention of dysphagia in India may also influence its effectiveness. Flay (1986) theorizes that effectiveness identifies if an intervention does more good than harm in a real life setting. Even a proven intervention strategy (feasibility, validity and efficacy) may still lead to different outcomes when conducted in real life settings. It may be because of differences in its availability or acceptance or due to the influence of various other factors such as environmental or social influences. Flay is of the opinion that health promotion programs need to be subjected to more

effectiveness trials. Therefore, effectiveness of an intervention method like TR in the management of neurogenic dysphagia needs to be investigated in real world settings because much of the information we have on the effectiveness of TR in real life conditions has come from studies conducted under controlled settings (Singal, Higgins & Wailee, 2014; Wells, 1999).

Imbibing the concept of effectiveness trials, it is deemed necessary to investigate the effectiveness of an ecologically valid TR for the assessment and primary management of neurogenic dysphagia in a resource constrained country. The results obtained from such an evaluation in real life settings will be more useful for clinicians than results obtained under controlled settings to implement TR in a clinical setting (Streiner, 2002). This calls for a shift in the researcher's perspective to shift from a positivist paradigm to a constructivist one to position ecological validity in a resource constrained country, which means shifting ontologically, epistemologically and methodologically (Guba & Lincoln, 1994). Constructivism posits that a research is time and context bound while positivism concentrates mainly on quantitative research (Dieronitou, 2014). Positivism has been criticised on the basis that it neglects contextual, social and cultural factors. With this idea in mind, TR needs be investigated in a real life resource-constrained context to explain the effects of various variables that affect the ecological validity and its effectiveness.

1.2 Problem statement

A review of the concepts of TR, its use in the management of neurogenic dysphagia, its ecological validity and effectiveness suggested to the researcher that TR could be utilised to

address the needs of persons with neurogenic dysphagia in India. This is particularly because there are not many speech-language pathologists trained in the management of dysphagia in India. However, as much of our knowledge on the TR and its ecological validity has come from studies conducted in developed countries like Australia and USA, a question arises whether TR can be used to obtain similar results in a resource constrained country. There are valid concerns on how TR will be influenced by contextual, technology, cultural, social, infrastructural and patient-related factors that are specific to resource constrained countries. Therefore, prior to the implementation of a new service delivery system in such settings, it is necessary to understand its current status in a resource constrained country like India. This is also in light that the intervention of dysphagia can be complicated considering risks such as aspiration or choking. It needs to be understood whether TR is being used in any other field in this country, and factors that have affected its ecological validity.

1.3 Research question

This research attempted to answer the question - 'Is TR an ecologically valid and an effective tool in the assessment and primary management of neurogenic dysphagia in India?'

1.4 Study aims and objectives

The main aim of the study, based on the problem statement and research question, was to investigate the effectiveness of an ecologically valid TR system for the assessment and primary management of neurogenic dysphagia in India. This study was executed in three phases (explained in detail in Chapter Three) as different studies that are presented herein as

manuscripts that will be submitted as journal articles for publication, each of which have their own objectives as presented below.

1.4.1 Phase One- Literature Review and Conceptual Framework (Manuscript One)

1.4.1.1 Literature Review Aim

To explore the current literature available regarding the use of TR in the intervention of dysphagia using a narrative literature review.

1.4.1.2 Literature Review Objectives

- i. To investigate the current status and feasibility of TR in the assessment and/or management of dysphagia.
- ii. To identify the benefits and limitations of the studies to explain ecological validity of TR.

1.4.2 Phase Two- Ecological validity of TR in resource constrained countries (Manuscript Two)

1.4.2.1 Study One Aim

To investigate the ecological validity of TR in a resource constrained country such as India.

1.4.2.2 Study One Objectives

- i. To investigate the current status of TR in India through an understanding of the knowledge and attitude of TR personnel
- ii. To identify the variables that affect the ecological validity of TR in India based on the practice of the TR personnel.

1.4.3 Phase Three- Effectiveness of an ecologically valid TR for neurogenic dysphagia assessment (Manuscript Three)

1.4.3.1 Study Two Aim

To investigate the effectiveness of an ecologically valid TR for the assessment and primary management of neurogenic dysphagia in India

1.4.3.2 Study Two Objectives

- i. To compare the results obtained using CSE through an ecologically valid TR mode and face-to-face mode with the intention to identify if the scores are reliable.

- ii. To examine and explain the possible effects of the ecological validity variables i.e. patient, clinician, technology and context related factors on the effectiveness of TR in dysphagia assessment.

1.5 Summary of overall methodology

To answer the big question of this study, the researcher identified the need to follow an interrogative model of inquiry (Hintikka, 1981). By following this model, there was a need to answer smaller questions to fulfill the main aim of the study. The researcher has a main question to answer. The researcher followed a systematic method to construe the inquiry process and it does not matter how this is tallied, but allowed to explain the reasoning process. The reason why each phase had a chosen methodology is explained. By following this model, the epistemic aspects of the inquiry process led to formulating the methodology for each phase (Harmaakorpi & Mutanen, 2008).

The overall study followed a mixed methodology design (Creswell, 2009) as the study used both qualitative and quantitative methods for data collection and analysis, which were in correlation with aims and objectives, respective to each phase. This was novel in the field of TR, considering it is used for dysphagia assessment in a resource constrained country. The use of both qualitative and quantitative data to meet the overall aim of the study provided richness and rigor (Silverman & Marvasti, 2008). The results obtained from a phase were useful to formulate the data collection and analysis of the following phase. The results obtained helped in

highlighting the clinical relevance of the findings and its important contribution to the field of TR, specifically for the intervention of dysphagia in resource constrained country.

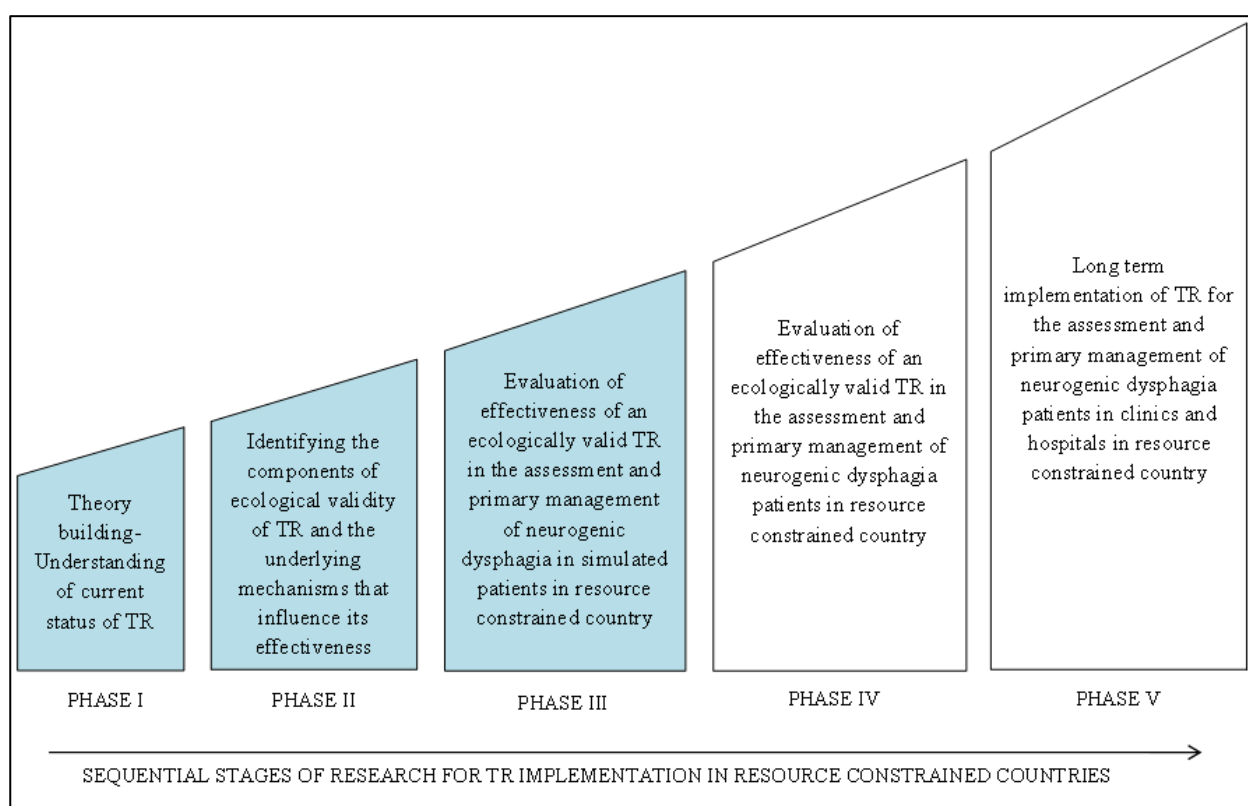


Figure 1.1: Stages of research for long term implementation of TR for management of dysphagia (adapted from Campbell et. al, 2000 and Craig, et. al, 2008)

The phases in figure 1.1 are adapted from the framework recommended for continuum of clinical evidence by Craig, et.al (2008) and clinical trials for drugs by Campbell, et. al (2000) when new treatment methods needed to be investigated. The first three phases of the continuum have been addressed in the current study, considering that the following phases would be beyond the capacity of this study. There is a need to examine the existing evidence to understand the use of TR for the intervention of dysphagia. This was carried out through a narrative literature review. Phase one helped in developing the conceptual framework for the overall study.

It is clearly recognized that changes are necessary while implementing a new intervention method in a resource constrained country; however, what is not clear is the nature of these changes and the mode of their implementation. A search for an answer to this led to phase two of the study which was developing a theoretical understanding of the different factors that can influence the ecological validity of TR by drawing information from a knowledge of the current status of TR (obtained from phase one) as well as by obtaining new evidence through an understanding of the knowledge, attitude and practice of TR personnel in a resource constrained country. The results from phase one helped in developing the research questions for phase two. Phase two was conducted through semi structured interviews (Silverman, 2006).

With the core theoretical concepts of ecological validity and effectiveness in place from phases one and two, TR needed to be modelled before a large-scale implementation which would include real patients with neurogenic dysphagia. Technology related, context related, clinician related and some patient related factors that were identified were incorporated in phase three to establish ecological validity of TR. Phase three required the implementation of TR for the assessment and primary management of neurogenic dysphagia on simulated patients (SP) to reduce the risk of any medical harm that could be caused during the study. SPs are used in the initial stage of implementation of TR in a resource constrained country due to the ethical decision of causing no harm to real patients (Charash, et. al, 2011), considering the TR is being used for the first time in such a context. Concept of SP was introduced by Barrows and Abrahamson in 1960s and was used in the field of medical education to give feedback and evaluate student performance (Barrows & Abrahamson, 1964). A well trained SP is considered to be equal to a real life patient, as explained by Beullens, Rethans, Goedhuys and Buntinx

(1997), considering that a real patient maybe unwilling or unable to sustain their participation, as well as there may not be easy access to a wide variety of a medical condition (Watson, Cleland & Bond, 2009). The use of an SP enhanced the safety of real patients, since the researcher got the exposure to real-life situations without posing any risk to real patients. Skills and procedures can be practised in a real clinical setting and the researcher can become aware of the effect of their actions on patients (Hughes, 2008). Use of SP have gained prevalent use in surgical education owing to its comparative lack of logistics and time restraints imposed by coordinating real patients (Figuerola, et. al, 2016). Use of SP has been found to be beneficial for high risk clinical scenarios where failure on the researcher's part may lead to grave consequences (Tuttle & Laakso, 2018; Nicksa, Anderson, Fidler & Stewart, 2015). The researcher acknowledged that the use of real patients in this study could lead to issues such as missing out on aspiration due to poor internet connection or power failure. A real patient may even choke on the food being used leading to grave consequences.

Contribution of SP is expanding into various other fields such as pharmacy, nursing and other health professions since they have the potential to be the highest fidelity simulators (Smithson, Bellingan, Glass & Mills, 2015). Current research supports the use of SPs in clinical skill development and competency assessment of students in the fields of nursing, pharmacy, dentistry, and chiropractic care (Zraick, 2002). Positive outcomes have also been reported about the use of SPs in allied health fields including community health education, dietetics, physical and occupation therapy (Brunner, Probst, Meichtry, Luomajoki & Dankaerts, 2016). Studies have used SP in laboratory settings, and “did not represent real populations who would include

those unable to travel due to chronic disability or aging, or those who lived in rural areas with insufficient access to rehabilitative services’’ (Mani, Sharma, Omar, Paungmali & Joseph, 2017).

Hagge, Nouredine, Brady & Ofstad (2015) used simulated patients to teach speech language pathology graduate students and undergraduate nursing students on inter professional collaboration for dysphagia management. Ward et. al (2015) aimed at studying the benefits of adding human patient simulation as part of university curriculum in paediatric dysphagia. The results demonstrated additive value in knowledge, skills and confidence obtained through this. It was rated as useful when preparing for clinical practice. Hence, it is reasonably assumed, based on the results of the studies that have used SPs (Smithson, Bellingan, Glass & Mills, 2015; Sharma, Ward, Burns, Theodoros & Russell, 2011) that using SPs will not adversely influence the ecological validity of the strategy being investigated.

Sharma, Ward, Burns, Theodoros and Russell (2011) used simulated patients (SPs) in their pilot study for investigating the feasibility of TR for online dysphagia assessment. The researcher used SPs in phase three which is a pilot phase of TR implementation. Phase three is necessary to progressively refine the design and incorporate the benefits and limitations in further phases four and five. Phase three adopted a mixed methodological design, wherein both quantitative and qualitative methods of analysis were conducted of the data obtained through observation of participants’ responses to the clinical swallow evaluation, with the main idea to understand the effect of the various factors that affect ecological validity on effectiveness of TR. However, incorporating phase four and five into the current study was beyond its scope.

1.6 Outline of the study

To summarize, early assessment and rehabilitation of adult neurogenic dysphagia by a dysphagia experienced SLP is crucial to prevent further medical complications (Falsetti et al., 2009). Due to various reasons like geographical, social and political factors and due to shortage of dysphagia experienced SLP, dysphagia services are not delivered adequately in resource constrained country. To meet the demands of dysphagia services in such settings, TR seems to be a good solution since it would help in delivering dysphagia services to adults with neurogenic dysphagia at faraway locations, even if the service is unavailable in their place. The concepts of ecological validity and effectiveness comes into picture, considering that previous studies of using TR for the intervention of dysphagia have been conducted under controlled settings in the economically developed countries. Hence, the current study began with understanding the available literature through a narrative literature review, as part of theory building. The study was divided into three phases, each of which being presented as journal publications (as show in in figure 1.2) and explained in detail in chapter three (methodology).

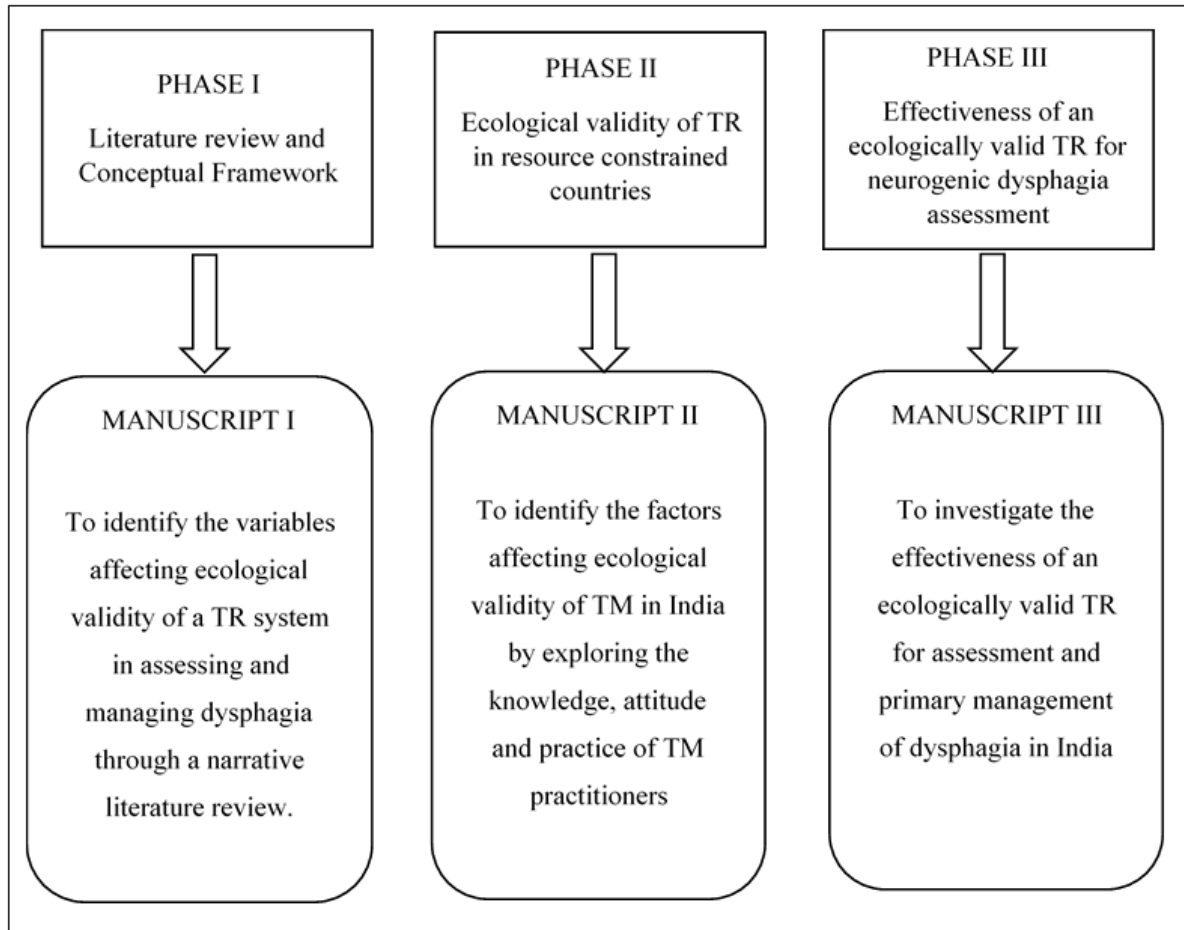


Figure 1.2: Diagram representing the three phases of the overall study

The phase one, which was the narrative literature review (Chapter Two) aids to understand the current status of the available research done using TR for dysphagia assessment and/or management. It will help to identify if TR has been feasible for the same. The narrative literature review aided in understanding the core concept of ecological validity from a theoretical point of view. Its primary purpose was to provide a comprehensive background for understanding current knowledge and highlighting the significance of new research (Cronin, Ryan & Coughlan, 2008). It inspired research ideas by identifying gaps in a body of knowledge, thus helping the researcher to determine the research question (Cronin, Ryan & Coughlan, 2008). It can also be helpful in

developing conceptual or theoretical frameworks (Coughlan, Cronin & Ryan 2007). Its strength is to comprehend the diversities of understanding around the research topic and the opportunity to speak with self-knowledge and reflective practice (Jones, 2004).

It helped to explore the benefits and limitations of all the studies, which could be directly associated with the factors that may influence the ecological validity of TR when using it in India. The chapter discussed the conceptual framework for the study. The literature review formed the basis for study one and hence study two. In the methodology chapter (Chapter Three), a detailed description of the two studies are being discussed, which includes the study sites, data collection process and data analysis of each study.

Based on the result obtained from the literature review in chapter two, there was a need to position ecological validity contextually in resource constrained country. Hence, in phase two (presented in Chapter Four), in depth semi structured interviews of TR personnel in India were conducted to identify the possible factors that can influence its ecological validity when using it in India, by investigating their knowledge, attitude and practice. The results obtained from the first two phases aided in the quantitative and qualitative analysis of the results obtained in phase three (Chapter Five). The quantitative data analysis identifies in TR is effective in the assessment and primary management of neurogenic dysphagia in India. The descriptive analysis of the results will help to explain the effect of the factors influencing ecological validity, on the effectiveness of TR.

In the synthesis and critique chapter (Chapter Six), the researcher links the results of the three phases to identify the ‘finding’ of the study. The chapter also presents the limitations of the investigations and recommendations for future research.

Chapter Two

Literature Review and Conceptual Framework

2.1 Overview of the chapter

A preliminary analysis of the infrastructure available in a resource constrained country like India such as primarily the non-availability of dysphagia experienced speech language pathologists (Shah & Gore, 2016) indicated that TR can be an answer to this issue. However, considering that past research in this area have been conducted mainly in economically developed countries, it is recognized that the results from these studies may not be readily applicable to a resource-constrained country. There are many imponderables when exporting a new technology to resource-constrained countries. There is a need to understand the present status of research not only in the global context, but specifically in the country which is the focus of this study. A review of the status of research on TR with a specific focus on the feasibility of using TR in the management of neurogenic dysphagia in a resource constrained country like India is the focus of this chapter. Considering that TR in the management of neurogenic dysphagia involves a new mode of service delivery, this chapter additionally focussed on the ecological validity of TR.

There are many studies on the applicability of TR in the field of physiotherapy, occupational therapy, nursing and speech language pathology. Russell et. al (2010) and Chumbler et. al (2012) have reported that TR is a valid and reliable method to provide physiotherapy intervention. Similar results have been reported in the field of occupational

therapy (Schein et. al, 2010; Barlow et. al 2009). A review of all these studies indicates that TR is a reliable and valid tool for managing issues related to physiotherapy and occupational therapy. Similarly, there are many studies in the field of speech language pathology supporting the feasibility of TR.

Early application of technology to assess and treat acquired adult speech and language disorders involved the use of telephone to treat patients with aphasia and motor speech disorders (Vaughan, 1976; Wertz et al., 1987), a computer controlled video laserdisc over the telephone and a closed circuit television system to assess speech and language disorders (Wertz et al., 1987), and a satellite based videoconferencing system to assess patients in rural areas (Duffy, Werven & Aronson, 1997). Constantinescu et. al (2010) assessed speech and voice disorders in Parkinson's disease and Grogan Johnson et. al (2011) conducted a pilot study for speech sound disorder intervention to school-age children using TR. These are a few studies to name.

The earliest study that used TR for management of dysphagia was by Lalor, Brown and Cranfield (2000). They were successful in conducting an initial assessment of the nature and extent of dysphagia in an adult case through a videoconferencing link. However, an intensive assessment was limited / or not possible because of an inability to physically assess the degree of laryngeal movement. A more sophisticated TR application for the assessment of swallowing was reported by Perlman and Witthawaskul (2002). Perlman and Witthawaskul employed the strategy of using real time videoflouroscopic examination via the Internet which enabled them to capture and display images in real time with only a three to five second delay. TR for dysphagia assessment and/or management has a history of nearly 17 years. There is a need to understand its

feasibility for addressing health-related issues and to identify the factors that have a bearing on its ecological validity. A thorough and analytical review of results published till date in this area will facilitate this understanding. A manuscript, reproduced below, has been submitted to the Dysphagia journal for publication.

2.2 Manuscript One

Feasibility of telerehabilitation in the intervention of dysphagia: a narrative literature review

Abstract

The article aimed to explore the current literature available regarding the use of TR in the intervention of dysphagia in the assessment and/or management of dysphagia using a narrative literature review. A database search was conducted on EBSCOhost, CINAHL and PubMed. The reference section of relevant articles was searched to find additional articles. 11 articles fulfilled the inclusion criterion. A narrative literature review and content analysis based on 11 points formulated for this study was undertaken to establish the feasibility and identify possible variables that affected the ecological validity of the telerehabilitation system. Telerehabilitation was found to be feasible in the intervention of dysphagia. Variables that can affect the ecological validity of the system were internet connectivity and bandwidth, availability of computer and related devices, knowledge of computer use by patient, caregiver and on-site clinician, the intervention of dysphagia skills of on-site clinician, cause and severity of dysphagia, and other comorbidities of patients. The study could identify the variables that affect the ecological validity of a telerehabilitation system. The narrative literature review also identified that it is a feasible method to assess and/or manage dysphagia.

Keywords: telerehabilitation, ecological validity, dysphagia

Introduction

India is witnessing an increase in various lifestyle related diseases, such as neuromuscular disorders (E.g. cerebrovascular accidents), cancer and traumatic brain injury. These usually cause dysphagia (Das et. al, 2007). Intervention of dysphagia (assessment and management such as diet modifications, feeding positions/strategies and dysphagia therapy exercises) are seldom available in resource constrained countries such as India, due to a range of geographical, social and political factors. While many studies have been reported on the use of telerehabilitation (TR) in dysphagia management in economically developed countries like USA and Australia, their ecological validity has not been examined for resource constrained country. Ecological validity is a form of external validity, and while the latter refers to the overall extent to which findings can be generalized across people, places and time, the former refers more specifically to the extent to which findings can be generalized to the settings and people in all societies (Roy & Kathleen, 2007). The term ecological validity was applied to the environmental context of research in psychology, and the impact the setting had on the study, was questioned by Brunswick (1942) and Lewin (1943) (Schmuckler, 2001). To obtain results that are ecologically valid, participants must be studied in the richness of their natural settings. The concept of ecological validity refers most narrowly to the degree to which the definition of a unit of analysis reflects the way that unit is defined in real life by people or natural features (Perkins, Florin, Rich, Wandersman, Chavis, 1990). Ecological validity has usually been studied in economically developed countries to establish if the methods, materials and setting of a study approximate the real world that is being examined (Schmuckler, 2001).

TR is a branch of telemedicine where rehabilitation services are provided using information and communication technology (Russell, 2007) This can include delivering rehabilitation services via information technologies, such as assessment, monitoring, intervention, supervision, education, consultation and counselling (Brennan et. al, 2011). Various studies have reported valid and reliable results regarding the effects of TR in the field of physiotherapy and occupational therapy to provide interventions (Russell, Blumke, Richardson & Truter, 2010; Chumbler et. al, 2012; Schein, Schmeler, Holm, Saptono & Brienza, 2010; Barlow, Liu & Sekulic, 2009)

TR in the field of speech language pathology is the use of technology to provide speech therapy services to under resource areas. It has been successfully used in various studies that involved assessing and/or treating various speech and language disorders. In the mid-1970s, one of the first use of TR services for speech therapy occurred at the Birmingham Veterans Administration Hospital in Alabama, USA (Houston, 2013). Dr. Gwenyth Vaughn developed a ‘tele-communicology’ project that provided remote evaluation and treatment for patients with speech, language and hearing disorders, which was typically done over the telephone. This was however without any visual contact of patients. This service delivery model, which included a full range of services, such as patient-clinician sessions: consultations between patient, clinician and consultant: and educational lectures for staff, was implemented as a supplement to traditional services, principally for follow up. There was significant reduction in cost and travel time and an increase in the number of patient-clinician contacts. In 1987, Wertz, et. al examined the reliability of diagnostic testing of adults by comparing three modes of assessment i.e. traditional

face-to-face, TR using a closed circuit television and telepractice using a video laser disc and telephone system (Houston, 2013), which included video and audio contact with the patients.

In 2000, Kully used videoconferencing service to manage stuttering, the results showing that this was useful for long term follow up, after the patients had received intensive treatment in their local clinic. The interactive videoconferencing format used in this study was suitable in the area of early intervention, where parents can be taught to manage a child's stuttering. This technology can also give practising clinicians the opportunity to link with specialist centres for consultations on particularly difficult or complex cases.

In 2001, McCullough showed that using TR helped to increase the knowledge of parents or caregivers about how to improve the communication skills of children with special needs and was found to be effective and reliable (McCullough, 2001). The benefits of this study were that parents were able to participate more fully in the therapy programme and the system enabled them to gain a greater understanding of their child's communication development through observation of their child in the nursery setting. They were also able to develop their confidence and skills by working with their child with guidance that was immediate but not invasive. The therapist was able to observe the communication environment in an unobtrusive manner and give advice on signing, therapy techniques and preparation for the session; it was also possible to provide more frequent support without the need for domiciliary visits or specialist parent training sessions.

A study by Sicotte, et. al in 2003 demonstrated that the full assessment and ongoing treatment of stuttering in children and adolescents can be successfully conducted via TR. All participants maintained at least part of their improved fluency during the six-month follow-up. However, it was observed from this study that TR is more demanding for the clinician, particularly when it comes to dealing with young children, and for parents, who must take an active role during treatment.

In 2003, Theodoros et. al conducted a preliminary validation of an internet based TR application for assessing motor speech disorders in adults with acquired neurological impairment using the Frenchay Dysarthria Assessment. The results indicated that TR had the potential to reliably assess motor speech disorders. However, technical issues such as poor quality of the web camera and lighting issues were a drawback in this study, leading to poorer levels of agreement on some variables.

Vestal et. al (2006) reported that TR can improve access to speech and language evaluation services that are relevant to dementia and other neurological diseases of the elderly. It can also be used to conduct evaluations in underserved areas. However, they reported that as the severity of speech, language and cognitive deficits increased, the more difficult it was for the patients to follow the instructions. A case study done by Constantinescu et. al (2010), revealed that the online delivery of Lee Silverman Voice Treatment for patients with speech disorders, such as idiopathic Parkinson's disorder, was valid and reliable, with the patients preferring online treatment over a face-to-face session. It was recognised that the perception of speech and vocal changes is more difficult in milder degrees of speech impairment. Occasional audio delays and poor video quality affected the outcomes.

The results of a study done by Rangarathnam et. al (2015) indicated that flow phonation exercises can be successfully used for patients with muscle tension dysphonia using TR. Significant improvements were found in perceptual, vocal fold function, acoustic and physiological parameters as well as nodule sizes and patient perceptions of voice related quality of life post treatment. Participants were satisfied with their first experience using TR, the results being similar to those from intensive voice therapy delivered in a conventional face-to-face format. Many studies have therefore reported the positive results of TR in speech language therapy. However, only a small percentage of speech language pathologists in the USA use TR for regular interventions due to issues such as poor accessibility to internet and limited technical support (Ward & Burns, 2014).

In resource constrained countries, such as India, where more than 60% of the population live in rural areas with limited access to medical facilities and specialized services, telemedicine is providing timely care, appropriate treatment and valuable medical assistance (Parikh, Sattigeri, Kumar, 2014). Developments in information technology, satellite transmission and broadband connectivity across India have enabled telemedicine to bridge the resource gap between the demand and supply of health care in rural areas (Mishra, Kapoor & Singh, 2009). The first telemedicine unit in India was based in Aragonda, and it pioneered the development of this technology in the country, with more than 400 centres now using the technology (Ganapathy, 2004). Telemedicine in India has developed in the fields of surgery, neurosurgery, ophthalmology, psychiatry, primary health care and rheumatology (Patnaik & Patnaik, 2015). As of 2009, the Indian Space Research Organization's satellite based telemedicine network included

315 hospitals, this consisting of 271 remote district hospitals or health centres that were connected to 44 specialty hospitals located in major cities (Mishra, Kapoor & Singh, 2009).

With an increase in adult neurogenic dysphagia in India and the dearth of dysphagia experienced speech language pathologists (SLP), new methods need to be considered to assess and manage these patients. TR appears to be a possible solution to overcoming the short comings. The current study details the various studies that have used TR to assess and/or treat dysphagia, through a narrative literature review to investigate its feasibility. The literature review further helped to identify the variables that affect the ecological validity of a TR system in assessing and managing neurogenic dysphagia in a developing country, such as India, which may need to be modified for the local context. Its ecological validity and effectiveness in assessing and managing neurogenic dysphagia need to be evaluated on an ongoing basis in future research studies.

This study therefore aimed to identify the variables that affect the ecological validity of a TR system in assessing and/or managing neurogenic dysphagia through a narrative literature review of relevant studies. The study also aimed to explore the current literature available regarding the use of TR in the intervention of dysphagia in the assessment and/or management of dysphagia using a narrative literature review. This was done by investigating the current status and feasibility of TR in the assessment and/or management of dysphagia and thereby, identifying the benefits (results) and limitations of the studies, which could possibly direct towards the factors that could influence the ecological validity of TR in the assessment and/or management of dysphagia.

Method

A comprehensive online search of peer-reviewed journals was conducted using Boolean operators 'and' and 'or' to extract the relevant articles using the main search terms of telerehabilitation, telemedicine, telepractice, dysphagia, swallow, deglutition and feeding. Thus, a search with the MeSH terms or keywords (telerehabilitation OR telemedicine OR telepractice) AND (dysphagia OR swallow OR deglutition OR feeding) was done. This was done on databases such as EBSCOhost, Cumulative Index to Nursing and Allied Health Literature (CINAHL) and PubMed, and the reference sections of each identified article were also reviewed to find additional material. Articles were screened by reading the abstracts using the following inclusion criterion, 1. only articles or dissertation/thesis in English, 2. that included patients or simulated patients with dysphagia, 3. and used telemedicine/telerehabilitation/telepractice to deliver at least one service (assessment or treatment) from a specialist or expert at one location to a participant with dysphagia at a remote location. The exclusion criterion was studies (literature reviews, reports or editorials) that were not in English. The year of publication was restricted to June 2016, and the titles and abstracts of potential papers were extracted, with the two independent reviewers being blinded during the screening process. To ensure the fidelity of the literature search, all inclusion criteria were applied.

The search identified nine relevant articles and one thesis, the latter being completed by Sharma (2012) and was publication based, with two articles being identified as relevant and included in this study. These final 11 studies represent a range of methods used as a part of TR. The study design consisted of a narrative review, which enabled the contents of selected studies

to be summarized from which conclusions can be made (Greens, Johnson & Adams, 2006; Jesson & Lacey, 2006). The articles were analyzed with respect to the following points developed by the researcher, based on the framework provided by Arksey and O'Malley (2005) and Cronin, Ryan & Coughlan (2008): 1. study aim; 2. study location; 3. description of the participants; 4. description of the assessment tools; 5. any comparison of assessment tool and if so, what they were; 6. resources used (costs, personnel, skills, internet connection details); 7. study results; 8. if the findings were generalized to a greater population (ecological validity); and 9. limitations. Questions 1, 3, 4, 5 and 7 addressed the issue of TR as a feasible method and questions 2, 6, 8 and 9 were designed to identify the factors that affected ecological validity.

Results and discussion

The search identified 11 articles that were included in this study, which were subjected to narrative content analysis based on the study aim. This resulted in the identification of two main areas of interest based on the study objectives, specifically feasibility of the intervention of dysphagia using TR and factors affecting its ecological validity.

Feasibility of TR in the intervention of dysphagia

An analysis of the results of all the studies showed that TR is a feasible method for the intervention of dysphagia (Table 2.1). The feasibility assessment was based on a comparison of test results done by a face-to-face clinician and the telerehabilitation clinician.

Table 2.1: Aims, results and location of the studies based on narrative literature review

TITLE OF STUDY	AIM	RESULTS
Ward <i>et. al</i> (2007): online SLP in Cairns, FTF SLP in Brisbane; Australia		
Assessment of communication and swallowing post laryngectomy: a telerehabilitation trial.	1. To test the improved visibility for stoma and voice prosthesis examination. 2. To examine the technical performance of a remotely delivered service 3. To measure patient and clinician satisfaction during a remote trial.	1. Image quality obtained via the freestanding camera was rated as lower than direct observation, but it was sufficient to assess the stoma and status of the voice prosthesis 2. High agreement (>80% PEA) in results by TR-SLP and FTF SLP. 3. High patient satisfaction (90%) and clinician satisfaction (100%) in using the TR system
Malandraki <i>et. al</i> (2011): FTF SLP was in Arkansas, TR SLP in University of Illinois; USA		
Teledynamic evaluation of oropharyngeal swallowing	To test the feasibility & clinical utility of a real time internet based protocol for remote, teleflourosopic evaluation of oropharyngeal swallowing.	1. High agreement in subjective severity ratings by TR- SLP and FTF-SLP (k=0.636) and in Penetration-Aspiration scale ratings (mean absolute difference= 1.1 points).Agreement in treatment recommendations was moderate to high, ranging from 69.3% to 100%.
Sharma <i>et. al</i> (2011): Lab settings within 2 separate rooms at University of Queensland; Australia		
Assessing swallowing disorders online- a pilot telerehabilitation study	To provide pilot information on the basic feasibility & validity of conducting dysphagia assessments via telerehabilitation	1. High levels of agreement (96.3-100%) in results by TR-SLP and FTF-SLP
Ward <i>et. al</i> (2011): 2 SLP in different rooms within same department; Australia		
Validity of conducting clinical	1. To determine the level of agreement between	1.Agreement between the T-SLP and FTF-SLP ratings for

dysphagia assessments for patients with normal to mild cognitive impairment via Telerehabilitation	online & FTF-SLPs about safety for oral feeding (full, modified oral or non-oral) and if on modified diet, the safe food/fluid recommendations. 2. To establish the levels of agreement between the TR-SLP & FTF-SLP	the oral, oromotor, and laryngeal function tasks revealed levels of exact agreement ranging from 75 to 100% ($k=0.36-1.0$), while the parameters relating to food and fluid trials ranged in exact agreement from 79 to 100% ($k=0.61-1.0$). Across the parameters related to aspiration risk and clinical management, exact agreement ranged between 79 and 100% ($kappa=0.49-1.0$). 2. High agreement (Ranging between 75-100%) between TR-SLP and FTF-SLP.
Burns <i>et. al</i> (2012): 2 SLP departments of Central Integrated Regional Cancer Service in Queensland which are 100km away; Australia		
A pilot trial of a speech pathology telehealth service for head and neck cancer patients.	To explore the feasibility of providing access to specialist speech pathology services via telehealth for patients with head and neck cancer	1. Patients were successfully managed. 2. High satisfaction (55-63%) by patients. 3. High satisfaction (70-80%) by both clinicians. 4. Financial benefits for the patients. 5. Opportunity for workforce training & development through online case discussion & clinical consultation.
Ward <i>et. al</i> (2012): Australia		
Managing patient factors in the assessment of swallowing via Telerehabilitation	To examine the issues that potentially impacted on the service delivery of clinical dysphagia assessment via TR system	Patient factors (speech and/or voice impairment, behavioural issues, hearing impairment, motor disorders, etc.) were identified that can affect the TR assessment.
Malandraki <i>et. al</i> (2013): Greece and USA		

An international pilot study of asynchronous teleconsultation for oropharyngeal dysphagia.	To investigate whether an expert's consultation via telemedicine could improve the quality of care for dysphagia patients	<ol style="list-style-type: none"> 1. Good inter rater agreement (78-90%) on 8 diagnostic indicators of swallowing impairment. 2. High agreement ($P=0.003$, Kendall's tau= 0.67) on overall subjective severity index for all patients except one.
Ward <i>et. al</i> (2013): Online SP & TR SP in 2 rooms within same facility; Australia		
Evaluation of a Clinical Service Model for Dysphagia Assessment via Telerehabilitation.	<ol style="list-style-type: none"> 1. To examine the outcomes of a weekly dysphagia assessment clinic conducted via TR 2. To examine issues relating to service delivery & user perceptions. 	<ol style="list-style-type: none"> 1. High agreement in clinical decisions (regarding primary patient outcomes) made by TR-SLP and FTF-SLP (92-100%). High patient satisfaction (90%) and high clinician satisfaction (90%). 2. Key factors relating to screening patient suitability, having good general organization, and skilled staff were identified as facilitators for the service.
Malandraki <i>et. al</i> (2014): USA		
Telepractice for Paediatric Dysphagia: A Case Study	<ol style="list-style-type: none"> 1. To examine the feasibility of providing dysphagia treatment via TR in a paediatric patient. 2. To examine whether this treatment program was effective for the child under study. 	<ol style="list-style-type: none"> 1. Patient showed improved oral acceptance of eating related objects & a variety of foods (behavioural variable), timing of voluntary saliva swallows & aerophagia levels, (swallowing variables) & quality of life. 2. Follow up interview analysis showed that most skills were retained or improved 1month post intervention. 3. TR intervention was feasible and effective.
Ward <i>et. al</i> (2014): FTF-SLP & TR-SLP in 2 rooms within same facility; Australia		

Impact of dysphagia severity on clinical decision making via Telerehabilitation	To examine how dysphagia severity impacted on either (a) clinical decision making for safe oral intake or (b) clinician perceptions of CSEs conducted via telerehabilitation.	<ol style="list-style-type: none"> 1. Acceptable levels of agreement were observed between raters decisions regarding oral/non oral intake and safe food and fluids 2. High agreement (90%) in CSE between TR-SLP & FTF-SLP. 3. For a small but significant ($p < 0.5$) proportion of patents in the severe dysphagic group, clinicians disagreed they were able to satisfactorily and competently assess using the telerehabilitation system.
Burns <i>et. al</i> (2016): 2 rooms within same building; Australia		
Conducting Real-Time Videofluoroscopic Swallow Study via Telepractice: A Preliminary Feasibility and Reliability Study.	To test the feasibility and reliability of using a TR system to enable live VFSS assessment	<ol style="list-style-type: none"> 1. High levels of agreement (75-100%) between TR-SLP & FTF-SLP regarding swallowing parameters (range = 75–100 %; $k = -0.34$ to 1.0) & management decisions (range = 70–100 %, $k = 0.64$–1.0). 2. High satisfaction (95%) by clinician. 3. Findings support the potential to conduct live VFSS assessment via a TR model.

PEA- percentage exact agreement, FTF-face to face, SLP-speech language pathologist, TR- telerehabilitation, CSE-clinical swallow evaluation, VFSS- videofluoroscopic swallowing study, k- Kappa score

Of the eleven studies identified, nine of them used a comparison tool in addition to TR, which was the face to face assessment of dysphagia of the patients, while two did not as seen in Table 2.2. All the studies showed high agreement between the clinical decisions taken. It is also seen that the studies had different aetiologies causing dysphagia, with a variety of intervention methods being used. Nevertheless, TR was found to be a feasible method with high levels of patient satisfaction being reported in three studies (Ward et. al, 2007; Burns, et. al, 2012; Ward, Burns, Theodoros & Russell, 2013) and four indicating high clinician satisfaction levels (Ward et. al, 2007; Burns, et. al, 2012; Ward, Burns, Theodoros & Russell, 2013; Burns, Wards, Hill, Phillips & Porter, 2016).

Table 2.2: Instrument used, comparison instrument used and resources required for the studies

AUTHOR	INSTRUMENT USED	COMPARISON INSTRUMENT USED	RESOURCES REQUIRED FOR THE STUDY
Ward <i>et. al</i> (2007)	Australian therapy Outcome Measures(AusTOMs), modified satisfaction questionnaire	Australian therapy Outcome Measures(AusTOMs) by FTF-SLP	TR-SLP, FTF-SLP, TR system
Malandraki <i>et. al</i> (2011)	Videofluoroscopic evaluation	Videofluoroscopic evaluation by a FTF-SLP	FTF-SLP, 2 TR-SLP, VFSS machine, TR system
Sharma <i>et. al</i> (2011)	Clinical swallow examination by a TR-SLP	Clinical swallow examination by a FTF-SLP	TR-SLP, FTF-SLP, assistant at site of study, 2 consultation rooms, TR equipment
Ward <i>et. al.</i> (2011)	Clinical swallow examination by a TR-SLP	Clinical swallow examination by a FTF-SLP	TR-SLP, FTF-SLP, assistant at site of study, 2 consultation rooms, TR equipment
Burns <i>et. al</i> (2012)	Patients received either communication intervention or swallowing intervention via TR	None	TR-SLP with experience in head and neck cancer, one FTF-SLP with limited knowledge in head and neck cancer, TR system
Ward <i>et. al</i> (2012)	Clinical swallow examination by a TR-SLP	Clinical swallow examination by a FTF-SLP	FTF-SLP, TR-SLP, TR system
Malandraki <i>et. al</i> (2013)	VFSS done by on-site clinician in Greece	VFSS images reviewed by SLP in United States of America	FTF clinician (radiologist or ICU specialist), TR-SLP, VFSS machine, website to share patient information and VFSS recordings

Ward <i>et. al</i> (2013)	Clinical swallow examination by a TR-SLP	Clinical swallow examination by a FTF-SLP	FTF-SLP, TR-SLP, TR system
Malandraki <i>et. al</i> (2014)	Close ended intensive pediatric swallowing TR program	None	TR-SLP, research assistant, parents of the patient, systematic written instructions for the parents prior to each session, TR computer with three tele-applications- Adobe Connect, Skype and Vsee
Ward <i>et. al</i> (2014)	Clinical swallow examination by a TR-SLP	Clinical swallow examination by a FTF-SLP	FTF-SLP, TR-SLP, TR system
Burns <i>et. al</i> (2016)	VFSS done by TR-SLP	VFSS done by FTF-SLP	FTF-SLP, TR-SLP, TR system, VFSS machine, radiographer to perform VFSS

FTF-face to face, SLP-speech language pathologist, TR- telerehabilitation, VFSS- videofluoroscopic swallowing study

Factors affecting ecological validity of the TR system

Regarding its use in the intervention of dysphagia, several concerns were noted if the study settings described in previous studies, provided similar results to a real life condition (effectiveness), and if similar settings could be used across any country, which is, ecological validity. Although telemedicine has been in use in India for over a decade, only a few studies have been reported with the use of TR (Mishra, Kapoor & Singh, 2009; Sinha, Tiwari & Kataria, 2012; Rao, Iyer & Anap, 2012). However, its use to assess and/or manage dysphagia has mainly been studied by various researchers in economically developed countries, with very few being done in resource constrained nations.

Based on the analysis of the studies included presented in Table 2.1, they were all conducted in economically advanced countries, the results being valid and efficacious only for their geopolitical areas, especially the USA and Australia. Only one study was done across two countries, these being the USA and Greece (Malandraki et. al, 2013) with the swallow assessment being done in a face-to-face setting in Greece, and the video being sent to a SLP in the USA for in depth analysis. Thus, the results can be ecologically valid, as the study was done in real life settings.

Ward et. al (2007), Burns et. al (2012) and Malandraki et. al (2013) conducted their studies with the onsite and TR SLP being far away from each other. All the other studies were conducted in clinical settings and in rooms within the same building or department (Sharma, Ward, Burns, Theodoros & Russell, 2011; Ward, Sharma, Burns, Theodoros & Russell, 2011; Ward & Burns, 2014; Ward, Burns, Theodoros & Russell, 2013; Burns, Wards, Hill, Phillips & Porter, 2016). Thus, ecological validity was not considered in any of

the other studies included in this paper. Various factors can affect the ecological validity of a study, the studies indicating that the resources used (Table 2.2) and various limitations affecting the ecological validity (Table 2.3).

Table 2.3: Limitations of the studies

AUTHOR	LIMITATIONS OF THE STUDY
Ward <i>et. al</i> (2007)	<ol style="list-style-type: none"> 1. Reduced visual quality reported. 2. Occasional audio break up reported during the TR assessment sessions
Malandraki <i>et. al</i> (2011)	<ol style="list-style-type: none"> 1. There was 1-2 seconds delay in online transmission of images. 2. TR-SLP did not have access to the whole medical record of the patients due to patient confidentiality issues by the hospital. 3. Quality of images during online transmission was often reduced due to poor internet connectivity, overload of internet transmissions at high use times.
Sharma <i>et. al</i> (2011)	<ol style="list-style-type: none"> 1. Low bandwidth. 2. Use of standardized patients
Ward <i>et. al.</i> (2011)	<ol style="list-style-type: none"> 1. Two patients had breathy voice that was difficult to hear by TR-SLP. 2. One participant with mild cognitive impairment was not co-operative at times. 3. Low band width of internet connection. 4. Limitation of CSE to identify silent aspiration
Burns <i>et. al</i> (2012)	Not discussed
Ward <i>et. al</i> (2012)	The patient factors identified during the study did affect the assessment process

Malandraki <i>et. al</i> (2013)	<ol style="list-style-type: none"> 1. Use of a physician led to reduced depth in onsite assessment. 2. The TR-SLP had difficulty in deciding the next treatment recommendations based on the stored imaging sequences. 3. Frame rate was limited 14 frames/s. higher frame rates would allow more detailed examinations
Ward <i>et. al</i> (2013)	<ol style="list-style-type: none"> 1. Simulated model was used. 2. Some technical problems related to audio and visual quality. 3. TR assessment took more time than a face to face assessment
Malandraki <i>et. al</i> (2014)	<ol style="list-style-type: none"> 1. No generalizability. 2. No comparison with face-to-face therapy sessions was done. 3. Some of the measurements were completed based on the mother's response which could have led to bias
Ward <i>et. al</i> (2014)	<ol style="list-style-type: none"> 1. Cognitive and language deficits affected assessment. 2. Other comorbidities like hearing impairment, movement disorders, agitation, etc. affected the assessment
Burns <i>et. al</i> (2016)	<ol style="list-style-type: none"> 1. Testing across larger distances and using different networks may cause delay in data transfer leading to changes in image quality and communication efficiency. 2. Study was conducted within the same facility by creating a simulated remote access model. 3. It cannot be confirmed if higher or lower internet speeds would support good results. 4. Equipment and data network utilized incorporated latest technology and thus does not represent all possible equipment configuration

SLP-speech language pathologist, TR- telerehabilitation

Skills with regards to the intervention of dysphagia by onsite clinician. In most studies, the resources that were used were mainly a FTF-SLP, TR-SLP and an assistant who

was present at the patient's site, with only Malandraki et. al (2013) using a physician as an onsite clinician. Considering that TR is meant to be used to support underserved areas, the availability of an SLP is not always necessary, but the knowledge and skills of the onsite clinician with regards to the intervention of dysphagia is important, as it can affect the ecological validity of the TR system. In the study done by Malandraki et. al (2013), as a physician was the onsite clinician, an in depth traditional dysphagia assessment could not be done, due to their reduced knowledge in this regard.

Availability of computers and other accessories. Resources in terms of availability of computers in remote areas in a resource constrained country such as India can affect the ecological validity of the TR intervention. India being a developing country, the availability of personal computers especially in underserved areas will be less. Remote areas in India may not have access to these resources and patients, caregivers and/or on-site clinician's ability to use the computer and their accessories can affect the ecological validity. Studies included in this article have been done in controlled settings in economically developed countries, wherein all the resources will be available, due to the well-resourced infrastructure of the settings.

Knowledge of use of computers and other accessories. Computer literacy in India is estimated to be 6.15% (Manzar, 2012). The knowledge regarding their use may well be limited among people in rural areas, since computer education is still not accessible in rural parts of India. Poverty is also a factor that affects this. Fair knowledge of use of computer by the onsite clinician or the helper at patient's side is necessary to make TR feasible and ecologically valid.

Internet connection and bandwidth. The quality of images was found to be low if the internet bandwidth was low (Ward et. al, 2007; Malandraki et. al, 2011) and Ward et. al (2007) reported occasional audio breaks during the TR session. Burns, Wards, Hill, Phillips and Porter (2016) also reported that using TR across larger distances and using different networks caused delay in data transfer, leading to reduced image quality and communication efficiency. These factors need to be examined when using TR technology within India, considering its large and varied geography.

Causes and severity of dysphagia and other comorbidities. Patient factors such as the aetiology, and the cause and severity of dysphagia, appear to have affected the results and thus the ecological validity of TR (Table 2.4). This was discussed in the studies by Ward and Burns (2007) and Ward, Sharma, Burns, Theodoros and Russell (2012), who stated that the severity of dysphagia and other comorbidities, such as cognitive impairment, speech, language impairment and hearing impairment, did influence the study result, and that silent aspirations could not be detected. The study participants all had dysphagia with various etiologies, two had head and neck cancer (Malandraki, McCullough, He, McWeeny & Perlman, 2011; Burns et. al, 2012), one was a paediatric patient (Malandraki, Roth & Sheppard, 2014), and another had a laryngectomy (Ward et. al, 2007). The remaining six studies did not specify the aetiology or the cause of dysphagia.

Table 2.4: Causes and severity of dysphagia and other comorbidities of participants

AUTHOR	CAUSES AND SEVERITY OF DYSPHAGIA AND OTHER COMORBIDITIES OF PARTICIPANTS
Ward et. al (2007)	10 laryngectomy patients

Malandraki <i>et. al</i> (2011)	32 patients with a primary diagnosis of cerebrovascular accident or head/neck cancer
Sharma <i>et. al</i> (2011)	10 simulated patients portraying a range of swallowing difficulties
Ward <i>et. al.</i> (2011)	40 patients presented with mild to severe dysphagia with various etiologies.
Burns <i>et. al</i> (2012)	18 head and neck cancer patients
Ward <i>et. al</i> (2012)	40 patients presented with mild to severe dysphagia with various etiologies.
Malandraki <i>et. al</i> (2013)	17 patients with dysphagia due to various etiologies
Ward <i>et. al</i> (2013)	100 patients with dysphagia
Malandraki <i>et. al</i> (2014)	A 6years 6 months old child diagnosed with Opitz BBB/G Syndrome and Asperger's Syndrome
Ward <i>et. al</i> (2014)	One hundred patients (25 non dysphagics and 25 mild, 25 moderate, and 25 severe dysphagics) with various etiologies
Burns <i>et. al</i> (2016)	Twenty adult patients with dysphagia

Ethical issues related to TR. The researcher identified various ethical aspects of TR which were autonomy, privacy, confidentiality, consent, equality of service availability and beneficence. Autonomy of the patient and the caregiver should be acknowledged when conducting TR, considering that the patient may feel vulnerable during TR. Privacy and

principles of basic privacy protection in TR is crucial. Collecting, processing, storing and disclosing personally identifiable information when using TR bring forth concerns of information privacy (Ruotsalainen, 2010). In TR, confidentiality should be maintained by not disclosing patient details at any point of time. This enables health care professionals to provide good care to their patients (Stanberry, 2006).

Consent from the patient or the caregiver is always needed when e.g. sharing photos or videos of patient or personal historical information (Fleming, Edison & Pak, 2009). Getting an informed consent from a patient who has a cognitive impairment is particularly challenging. The patient may not fully understand why telecare device is needed, how it may affect them and how it is used. The following steps should be made when introducing TR as a possible way of treatment; professionals should always describe equipment and services that are used, how TR services differ from traditional services, what kind of consequences, positive or negative, using technology may have and how TR may have limits concerning confidentiality (Denton, 2003).

TR can offer patients a better access to a higher quality of services and at the same time it makes offering these services more cost effective (Tindall et. al, 2008; Burns et. al, 2017) to the provider. More efficient use of health care resources will probably enable a fairer access to services by patients (Ashcroft & Goddard, 2000). By beneficence, TR can reduce health care costs, increase patient access to health care services, improve the quality and continuity of health care and reduce the loss of work time, travel and costs from the patients' point of view (Miesperä, Ahonen & Reponen, 2013). They can also improve the patient satisfaction, provide a sense of security to patients and help patients suffering from chronic

illness and disease to empower themselves and be more active in their care. However, TR should be careful regarding non-maleficence, i.e. causing no harm or injury to the patients.

Conclusion

In India, with its diverse landmass (India is the seventh largest country in the world), large population (second most populated country in the world) and shortage of dysphagia experienced SLP; TR can be used to link the health care providers with a SLP who has had dysphagia experience at a distance. It can improve the quality and accessibility of care by allowing the SLP at the distant location to evaluate, diagnose, treat and provide follow up care to patients. This can help to improve the patient's quality of life and achieve the goal of 'health for all' in terms of dysphagia management. However, this may be affected by factors such as internet connectivity and bandwidth, availability of computers, knowledge of using computers, dysphagia related skills of the onsite clinician and the severity of dysphagia and other comorbidities.

Studies done in the economically developed countries have investigated the TR system in assessing or managing dysphagia in controlled settings, hence doubting its ecological validity and effectiveness. Thus, these need to be evaluated to determine if TR can deliver the desired outcome in a real life setting and in any country, as per the requirements of effectiveness and ecological validity. As Miller and Shinn noted: 'local origins are no guarantee for program success and local values may sometimes merit changes' (Miller & Shinn, 2005). Thus, the analysis indicated the need for a study to be conducted within a resource constrained country such as India to establish the effectiveness and ecological validity of TR in the intervention of dysphagia.

The result obtained through the narrative literature review shows that there is consensus in the literature that TR is a feasible method for the intervention of dysphagia. However, a gap in knowledge regarding the effectiveness of using TR in the intervention of dysphagia, in resource constrained countries was identified. The study could identify the possible variables that can affect the ecological validity of a TR system. The variables need to be used to accommodate and improve its ecological validity which needs to be investigated to establish its effectiveness in assessing and managing dysphagia. This calls for further research to assess the effectiveness of an ecologically valid TR system in the assessment of neurogenic dysphagia in India.

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2.3 Summary of the literature review

The idea for the present study originated from the observation that there is a dearth of dysphagia experienced SLPs in resource constrained countries. Hence, the strategy of TR was considered as a solution that can address many of the health-related issues in resource constrained countries. TR has already found application in the fields of physiotherapy, occupational therapy and speech language pathology in the economically developed countries, was considered for trialling in resource constrained countries. The purpose of this chapter was to document and analyse published research findings on the application of TR in the area of speech-language pathology.

The narrative literature review aided the researcher to identify that TR is a feasible method for the intervention of dysphagia. In addition, this review highlighted the gap in knowledge on the use of TR for the intervention of dysphagia in resource constrained country as there are no studies reported. As has been mentioned repeatedly, most of the studies on TR and its applications in health care have been conducted in the economically developed countries and under controlled settings. Thus, there is a question mark on the ecological validity of TR in the management of dysphagia. Hence, the researcher came to believe that most studies viewed TR from a positivist paradigm wherein the concept of TR was being investigated independent of any related factors that could have otherwise influenced its performance in a real life setting (Guba & Lincoln, 1994).

There is a need to shift our focus to a constructivist paradigm when considering the use of TR in resource constrained countries, since subject interactions with the world and other external variables can influence its effectiveness (Guba & Lincoln, 1994). This means

that meaning is constructed and not discovered (Gray, 2004). Constructivism believes in collecting data in real life and seeks to understand the subjective influences and interpretations (Broom & Willis, 2012) and it is believed that events shape each other (Wilson, 2000). This ontological and epistemological view was obtained by analysing the existing literature, which indicated that there could be many variables that can affect the ecological validity of TR. These factors were identified as patient, clinician, technology and context related factors. The constructivist paradigm aided the researcher to group the answers obtained from the data collection points (developed based on the framework provided by Arksey and O'Malley, 2005; Cronin, Ryan & Coughlan, 2008). Patient and clinician factors were identified when information regarding the participants, assessment and comparison tools was identified. Technology related factors were identified with the information obtained from the resources used and context related factors were identified with the locations in which the studies were conducted. The limitations of the studies assisted to identify the patient, clinician, technology and context related factors.

There are many studies, mainly in the field of neuropsychology which have recognized the significance of ecological validity of their tools and have attempted to enhance it. A literature review conducted by Chaytor and Schmitter-Edgecombe (2003) suggested that most neuropsychological tests have only a moderate level of ecological validity when predicting real life cognitive functioning. They recommended continued investigation into factors such as the effects of the population being assessed, severity of the illness and time of injury (all being patient related factors) and the person completing the tests (clinician related factors) for their influence on ecological validity.

Van Ryckeghem (2017) identified the importance for real life settings in assessing the effect of acute or chronic pain on specific cognitive tasks to improve its ecological validity. This is perhaps, the first study to identify the importance of context related factors on ecological validity. Crist (2015) described the need to consider ecological validity of occupational therapy tools during practice and research. There was limited relationship between the current standardised tools and real life functioning. Saini and Polak (2014) investigated the need for parent child interaction observations to be done in a home visit or in natural environments where usually such interactions occur.

Hence, the researcher identified that the literature review augmented her idea that ecological validity of TR needed to be identified and thus its effectiveness when implementing it in a resource constrained countries, because the patient, clinician, technology and context related factors do play a major role. This literature review indicated that the assumption of the researcher on the ecological validity of TR and its effectiveness is valid.

2.4 Conceptual framework for the study

The overall concepts of this study were identified to be ecological validity and effectiveness of TR in relation to patient, clinician, technology, and context related factors.

2.4.1 Patient related factors

Ward et. al (2011) and Ward et. al (2014) observed that the medical diagnosis of the patient and other associated comorbidities had an influence on the outcomes of using TR,

though five out of the eleven studies did specify the aetiology of the participant. However, they have not analysed the effect of patient related factors on the results they obtained. This brings the researcher to agree that TR cannot be used by excluding patient factors. An example to quote could be from the study conducted by Ward et. al in 2011, wherein they showed that cognitively impaired participants with dysphagia were unable to follow the instructions provided by the TR- SLP. This indicates that TR cannot be used by excluding patient-related factors as they influence the performance of the patients, since they do influence the performance of the patients and thus the final results obtained.

2.4.2 Clinician related factors

Clinician related factors can include the professional skills of both the TR personnel, who is a SLP in this study, as well as the FTF clinician. The latter could be a SLP or a doctor or any other medical professional. As there may not be many dysphagia experienced SLP in a resource constrained country, many times it would be a medical doctor or an SLP with no or less experience in dysphagia who would identify a patient with dysphagia and that he needs intervention by a dysphagia experienced SLP. In the study done by Malandraki et. al (2013), a physician with no experience in dysphagia was on site with the patient and hence had reduced knowledge regarding the intervention of dysphagia. Clinician factors also include the computer literacy of both the FTF and TR personnel.

2.4.3 Technology related factors

Good internet connection, its bandwidth, availability of computers and related accessories play a vital role in determining the ecological validity of TR, since TR cannot

happen without these. Such technology and equipment may not be available in resource constrained countries particularly in their underserved areas. Improper technology can affect the audio-visual clarity of the videos during TR. This was raised by Ward et. al (2007), Malandraki et. al (2011), Ward et. al (2013) and Burns et. al (2016) wherein their results affected. As Malandraki et. al (2011) stated quality of images were usually diminished during high use times due to overload of internet.

2.4.4 Context related factors

The effectiveness of TR is influenced by conditions such as geographical, political, social and cultural factors in a resource constrained country. Øvretveit et. al (2011) have defined context as “...influences which interact with each other, and interact with the implementation process” [3, p 609]. Long distance TR can affect the TR outcome, as started by Burns et. al (2016). Most studies like those by Sharma, Ward, Burns, Theodoros and Russell (2011), Ward, Burns, Theodoros and Russell (2013), Ward and Burns (2014) and Burns, Wards, Hill, Phillips and Porter (2016) were conducted with the TR-SLP and FTF-SLP along with the patient being within the same building. Recurrent power failures that happen in resource constrained countries due to electricity shortage, adverse weather conditions, etc. can disrupt a TR intervention, which could lead to missing out on a vital information during an intervention.

Infrastructural factors (socio-political and economic factors) also influence the implementation of TR in a resource constrained country, which may be mostly attributed to a lack of initiative by the government. Legal issues such developing policies and procedures that govern the use TR in a resource constrained country is vital for the effectiveness of TR

(Math, Moirangthem & Kumar, 2015). Hence, research should be used as a method when a researcher wants to elucidate context related sources of variance in the individual to context relation that reflect the lived lives of people in particular places, developing within particular periods (Lerner & Callina, 2013).

This literature review compelled the researcher to change her thinking from a positivist to a constructivist paradigm. The constructivist paradigm demands that the ecological validity of TR needed to be established prior to implementing it in real life settings in a resource constrained country. This stipulation holds well whether it is TR for management of dysphagia or intervention for any other condition. The stipulation is true whether it is the area of speech pathology or physiotherapy, or occupational therapy. This review also brought out the importance of patient, clinician, technology, and context related factors in their influence on the ecological validity and thus, the effectiveness of TR. This has been illustrated in figure 2.1

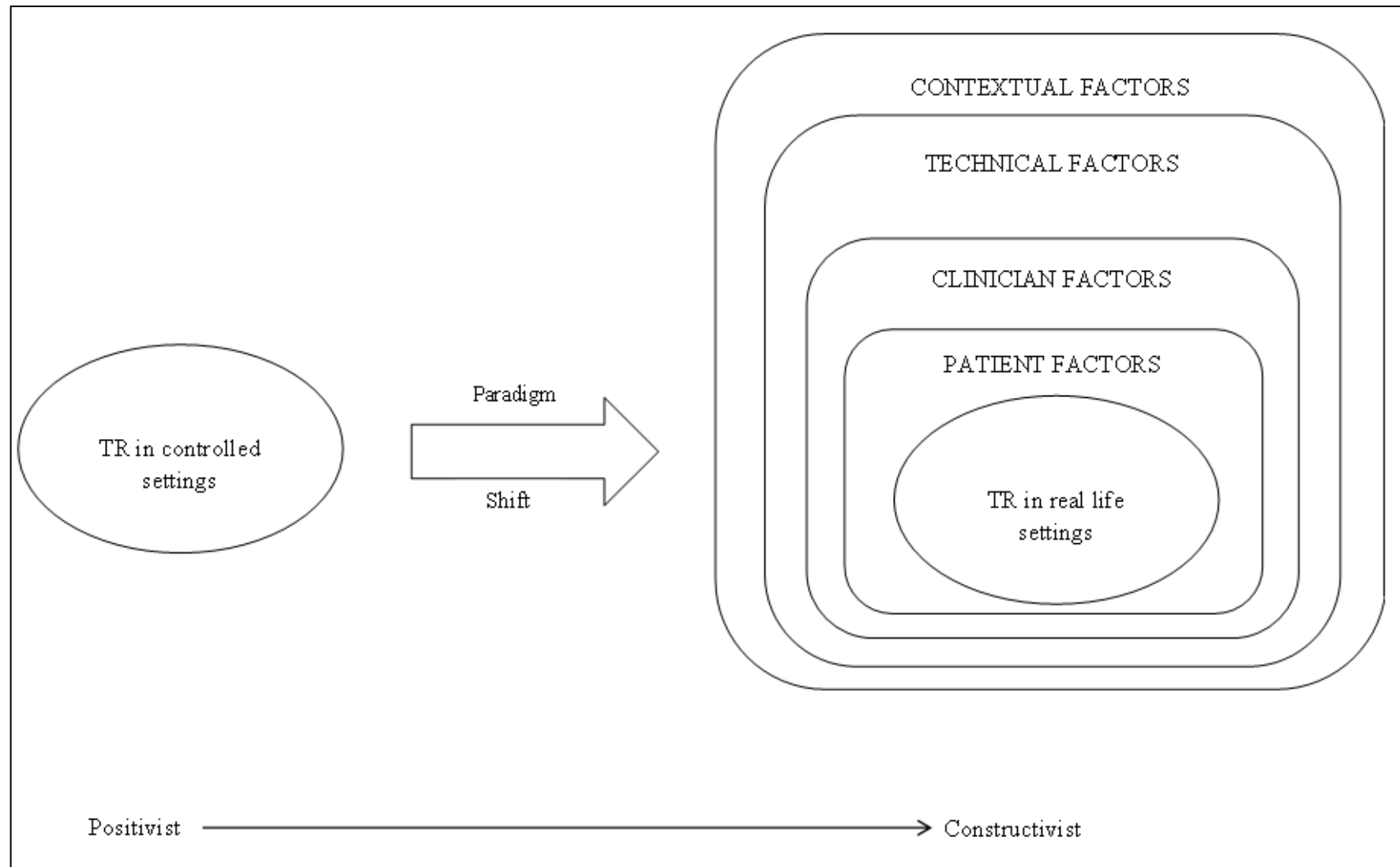


Figure 2.1: Conceptual framework of the study

2.5 Summary of the chapter

With the conceptual framework in place, the researcher identified the need to understand the various factors that can influence the effectiveness of an ecologically valid TR in neurogenic dysphagia assessment and primary management in a resource constrained country. A new mode of service delivery cannot be implemented in such a setting without considering and accounting for these factors, and hence, influencing the possible results obtained. Thus, the researcher identified the need to understand the current situation on TR in a resource constrained country. The researcher chose to do this by discussing the knowledge, practice and attitudes of the TR personnel in India (being her home country), which led to the study in phase two (in chapter four). There was a paradigm shift in the outlook of the researcher on this issue from a positivist to constructivist framework which necessitates recognition that there are many patient, clinician, technology, and context related factors that influence TR.

This shift necessitated the researcher to make appropriate methodological choices that were sensitive to the context as well as enabled her to make thick and in depth examination of the research problem being investigated (Tuli, 2011). This made the researcher to adopt the strategy of in depth semi structured interviews that encouraged the participants to speak freely and provided an insight into the status of TR in India. the interview questions were formulated to accommodate the factors of ecological validity and effectiveness (as seen in appendix 3). Questions under focus point A and B were developed to understand the context related factors. Focus point C, D and E were formulated to explore the patient related, clinician related and technology related factors that influenced ecological validity and hence the effectiveness of TR.

Chapter Three

Methodology

3.1 Overview of the chapter

This chapter summarizes the methodology of this study. The overall study followed a mixed methodology design, which was novel in the field of TR, considering its use for dysphagia assessment in a resource constrained country, and was conducted in several phases, which are discussed in detail below. It is believed that the use of both qualitative and quantitative data to test the aims of this study brought greater validity, richness and rigor to the findings. Each phase of the study resulted in a manuscript which will be submitted for publication to a journal. The proposed study was a part of a bigger idea that could be used for resource constrained countries, i.e. to implement the use of TR in the management of dysphagia in hospitals or clinics on a regular basis. The literature reported that while telemedicine offers great opportunities in general (World Health Organization, 2010), it could be even more beneficial for resource constrained countries such as India where access to basic care is of primary concern (Mars, 2011).

The idea was adapted from clinical trials for drugs (Campbell et. al, 2000) and continuum of clinical evidence by Craig, et.al (2008) when new treatment methods need to be investigated. On similar lines, the implementation of TR as an intervention tool in hospitals and clinics began with theory building, by exploring the available evidence on the use of TR for the intervention of dysphagia. A review of published data on the use of TR in the management of dysphagia indicated that TR is efficient. Most of these studies were conducted under controlled settings. An analysis of the limitations of these studies helped in

identifying the practical problems one may face while carrying out dysphagia management through TR.

The review helped us not only to understand the current status of TR in different countries, but also to strengthen the core concepts of ecological validity and effectiveness. It also helped us to affect a paradigmatic shift from a positivist to a constructivist one, which in turn was helpful in positioning, developing and conducting the following phase.

This led to the second phase (study one), which aimed to identify the current status of TR in India and also to identify the factors that could possibly affect the ecological validity of TR in a resource constrained country, considering that no study has been conducted in such a context and India was chosen. Though telemedicine has been in use in India for over a decade now (Sinha, Tiwari & Kataria, 2012; Mishra, Kapoor & Singh, 2009), only few studies have been reported with the use of TR. For example, Rao, Iyer and Anap (2012) conducted a study on the use of TR to treat osteoarthritis knee. There are no studies reported from India on the use of TR in the management of dysphagia. Thus, a study of the effectiveness of an ecologically valid TR system in the assessment of neurogenic dysphagia in a resource constraint context like India would be useful taking into consideration the growing population with neurological disorders in that country. Effectiveness should be evaluated to determine if the TR system delivers the desired outcome in a real life setting. As Miller and Shinn (2005) noted: 'local origins are no guarantee for program success and local values may sometimes merit changes' (p.180).

The knowledge obtained from the literature review and the semi structured interviews of TR personnel in India helped us to modify TR system to include almost all the variables

that affect the ecological validity of the TR system. This ecologically valid TR system then needed to be evaluated for its effectiveness in assessing dysphagia on SP, which was phase three (study two) of this study. Simulated patients were trained to simulate realistic patient-clinician scenarios and are defined by Barrows (1995) as “a normal person who has been carefully coached to present the symptoms and signs of an actual patient”.

This should ideally be followed by evaluating the effectiveness of the TR system in the management of dysphagia in real patients and then its implementation in real life setting, i.e. hospitals and clinics for use daily. However, this is beyond the scope of this study for logistical reasons. The results from this study will help to design a larger study on real patients in future.

The effectiveness of the TR system in the assessment and primary management of adult neurogenic dysphagia (using simulated patients) were studied taking into consideration the many limitations in a resource constrained country; like the lack of availability of electricity and communication lines which can restrict the use of TR in many locations, expense of computers, unavailability of computers to individual users and lack of decent bandwidth thus making internet connections slow and unreliable.

Table 3.1 is a summary of the different phases, aims, objectives, participants, data collection tools and methods of data analysis methods of the study.

Table 3.1: The aims, objectives, study participants, data collection tools and data analysis for each phase of the study

PHASE TWO				
Aim for Study one	Objectives for Study one	Study participants	Data collection tool for Study one	Data analysis for Study one
To investigate the ecological validity of TR in a resource constrained country such as India.	<p>To investigate the current status of TR in India through an understanding of the knowledge and attitude of TR personnel.</p> <p>1. To identify the variables that affect the ecological validity of TR in India based on the practice of the TR personnel.</p>	8 TR personnel in India	TR personnel semi-structured interview (Appendix 3)	Thematic data analysis using the themes that emerged from the literature i.e. patient, clinician, technology and context related factors

PHASE THREE

Aim for Study two	Objectives for Study two	Study participants for Study two	Data collection tool for Study two	Data analysis for Study two
To investigate the effectiveness of TR for the assessment and primary management of neurogenic dysphagia in India	<ol style="list-style-type: none"> 1. To compare the results obtained using CSE through TR mode and face to face mode with the intention to examine if the scores are reliable. 2. To examine and explain the effect of variables that influence ecological validity; that is, to see the effect of patient, clinician, technology and context related variables on the effectiveness of TR in the assessment and primary management of neurogenic 	One TR-SLP, FTF-SLP and 4 SP	Clinical swallow evaluation using the CSE proforma (Appendix 5)	<ol style="list-style-type: none"> 1. Inter-rater reliability using percentage exact agreement (PEA) and Cohen's Kappa (k) between the scores of the TR-SLP and FTF-SLP on the major categories of the CSE. 2. Descriptive case study analysis based on the themes of patient, clinician, technology and context related factors.

dysphagia

3.2 Phase Two- Ecological validity of TR in a resource constrained country

Review of published research on the use of TR in the management of dysphagia helped the researcher in identifying the variables that influence the ecological validity of TR services. The literature review also indicated that most studies investigated the efficacy of TR. This led the researcher to phase two with aims and objectives as stated below. Manuscript two was incorporated in this phase. Ethics approval was obtained for this study from the University of KwaZulu-Natal Biomedical Ethics Research Committee (BREC) with the reference number BFC452/15 (Appendix 1) and from NIMHANS ethics committee, in India with the reference number NIMH/DO/Ethics Sub-committee/30//2016 (Appendix 2).

3.2.1 Study aims and objectives

The primary aim of phase two was to investigate the ecological validity of TR in a resource constrained country. The objectives of phase two were as follows:

1. To investigate the current status of TR in India through an understanding of the knowledge and attitude of TR personnel.
2. To identify the variables that affect the ecological validity of TR in India based on the experience of the TR personnel.

3.2.2 Study design

The study followed an exploratory design (Gill, Stewart & Treasure, 2008; Maxwell, 2013; Taylor, Bogdan & DeVault, 2016). This design is predominantly used for theory building as opposed to hypothesis testing (Patton, 2002). The focus is on gaining insights and

familiarity for later investigation. This design is chosen when research problems are in a preliminary stage of investigation. Exploratory designs are often used to establish an understanding of how best to proceed in studying an issue.

Based on the KAP framework (Kaliyaperumal, 2004; Launiala & Kulmala, 2006; Pelto & Pelto, 1997; Richards, King, Selvaraj, McNicol, Brebner, & Godden, 2005; World Health Organization, 2008a; World Health Organization, 2008b; Yoder, 1997) the knowledge, attitude and practice of TR needed to be investigated before its implementation. It is as if a new intervention system is being implemented.

Knowledge means the ability of pursuing and using information, and understanding, learning, experiencing and identifying the study technologies (Badran, 1995). It is the capacity to acquire, retain and use information; a mixture of comprehension, experience, discernment and skill. The possession of knowledge requires a concept about the object and a perception of the concept. Education helps to acquire knowledge. Knowledge in this context refers to the knowledge about the TR, how to use it, its benefits and disadvantages. Thus, a question arises here on the training clinicians have received in India. Attitude indicates the result of making reactions via some ways in some situations; to observe and interpret according to certain predispositions (Badran, 1995). Practice indicates how knowledge and habit work together. It is the application of rules and knowledge that leads to action. Good practice is the art that is associated to the improvement of knowledge and is conducted in an ethical manner (WHO, 2008). Attitude refers to the attitude of clinicians and patients towards using TR for any intervention. Practice refers to the current practice of TR in a resource constrained country. Variations in practice may occur because of various

geographical, socio-economic, political reasons. There is a need to understand the current range of practice of TR in India and factors that affect its implementation.

3.2.3 Study method

Semi structured interview method, the most commonly used qualitative research method, was found to be successful in enabling reciprocity between the interviewer and participant (Kallio, Pietilä, Johnson & Kangasniemi, 2016). It enabled the interviewer to improvise on follow up questions based on the responses of participants (Harden, Garcia, Oliver, Rees, Shepherd, Brunton & Oakley, 2004; Rubin & Rubin 2005; Polit & Beck, 2010) and allowed space for participants' individual verbal expressions. The guiding questions were developed based on the knowledge, attitude and practice (KAP) framework with the intention to identify the factors that influence ecological validity of TR in India. The questions relating to the knowledge and attitude of the participants towards TR provided an understanding of the current status of TR in India. Responses of participants on the practice of TR enabled the researcher to understand the variables that influence its ecological validity.

3.2.4 Data collection tool

Data was collected using a semi structured interview schedule named 'TR personnel semi structured interview' (Appendix 3). The open ended questions of the semi structured interview were developed based on the aim of the study and the KAP model. The main subheadings related to the aim of the study were identified and questions for the semi structured interview were formulated.

The main questions were formulated based on the results from the literature review which helped to identify the limitations of the studies conducted in economically developed countries. The main questions covered the main content of the research subject and within them participants were encouraged to speak freely about their knowledge, attitudes and practices (Åstedt-Kurki & Heikkinen, 1994). These questions were on issues which were familiar to the participants besides being central to the study subject (Whiting, 2008).

Follow up questions were used to make the main themes easier for the participant to understand (Turner, 2010) and to direct conversation to the study subject (Barriball & While, 1994; Whiting, 2008; Baumbusch, 2010; Turner 2010; Rabionet, 2011). Most follow up questions were spontaneous based on the participant's answer (Whiting, 2008; Turner, 2010; Chenail, 2011). As a spontaneous follow up question, the interviewer asked participants to expand on some particular point that came up in the interview, by asking for more information (Whiting, 2008) or an example of the issue (Dearnley, 2005). Examples of verbal probes included repeating the participant's point, expressing interest with verbal agreement (Whiting, 2008; Turner, 2010) or giving the impression that the interviewer was aware of certain information. Non-verbal probing referred to remaining silent and allowing the participant to think aloud (Whiting, 2008). All interviews were in English and the interview proceedings were audio-recorded.

After the interviews, the audio tapes were listened to and notes were taken about general findings and emerging themes. The validity of the noting made by the researcher was checked for its correctness by comparing it with the noting made by two other independent researchers. The comparison showed high agreement between the two noting.

3.2.5 Study participants and sampling

The main participants of study two were TR personnel working in India. Two psychiatrists and six speech language pathologists who are using TR daily were selected through purposive sampling. Personnel with less than 1-year experience in TR were excluded. Purposeful sampling is a technique widely used in qualitative research for the identification and selection of information rich cases to make the most effective use of limited resources (Patton, 2002). This involves identifying and selecting individuals or groups of individuals who are especially knowledgeable about or experienced with the phenomenon of interest (Creswell & Plano Clark, 2011).

Recruiting speech language pathologists practicing TR exclusively was not possible as there are only a few such professionals in India. In addition, there was also an instance of a speech pathologist (practicing TR) not giving consent for participation in the study. Thus, other rehabilitation professionals such as two psychiatrists using TR were also identified. They provide TR services to rural health centres. One SLP had her own private TR service and the other 5 SLPs worked in a pioneer education institute that provided TR services to remote patients in India and education to other speech and hearing institutes.

Participants were contacted via email and informed consent was sought from them. They were informed on the purpose of the study, confidentiality of the interview/data, and assurance that no information would be disclosed (Appendix 4). Each interview, which lasted an hour, was done through Skype® since the interviewer was in Abu Dhabi (United Arab Emirates) and the interviewees were in India. Interviews were done in English and were all audio recorded.

3.2.6 Study location

TR personnel were chosen from India. The researcher, who was in Abu Dhabi (United Arab Emirates), conducted the interview through Skype®.

3.2.7 Data collection process

Interviews were done individually, in English, and at a date/time convenient to the participants. Informed consent was obtained to conduct the interview and to audio-record the proceedings. Audio recordings were made for all the interviews. After the interviews, the audio recordings were listened to and transcribed. Notes were taken about general findings and emerging themes. All identifiers (i.e. name of the participant, name of institute they work for, etc.) were removed from the transcripts. The validity of the noting made by the researcher was checked for its correctness by comparing it with the noting made by two other independent researchers. The comparison showed high agreement between the noting.

3.2.8 Data analysis

Thematic analysis was done which allowed the researcher to build theory through an analysis of the various data sets (Miles & Huberman, 2014). The researcher used an inductive approach for the analysis as this not only allowed themes to be identified from the data that was collected, but also helped in generating new concepts/theories. The main reason for using an inductive approach was to condense extensive raw text data into a brief, summary format and to establish clear links between the study objectives and the summary findings derived from the raw data (Thomas, 2006). This study design allowed for simultaneous data

collection and analysis, permitted development of codes, and included memo writing and making comparisons between the codes and categories (Charmaz, 2007).

The transcripts were entered on NVIVO 1.0, a computer software package by listening to the audio recorded interviews and notes were taken about general findings and emerging themes, which helped the researcher to become familiarized with the data. The validity of the noting made by the researcher was checked for its correctness by comparing it with the noting made by two other independent researchers. The comparison showed high agreement between the two noting.

Subsequently, preliminary codes were identified and collated from all the data sets, which were then combined under various themes that were established (Miles and Huberman, 2014). Further refining and defining of themes were done to identify various sub themes. The themes and sub themes were later grouped under main categories of knowledge, attitude and practice. Continuous comparison of the data enabled comparison of any newly collected data with previous data from other other interviews, coding, categorizing, delineating categories and connecting them (Boeije, 2002). Key findings were reported under each main theme by using appropriate verbatim quotes to illustrate those findings.

3.2.9 Trustworthiness of the study

The following criteria were used to ensure the trustworthiness of the qualitative study.

1. *Credibility*: Credibility establishes whether the study findings represent information drawn from the participants' original data and is a correct interpretation of the

participants' original views (Graneheim & Lundman, 2004; Lincoln & Guba, 1985). The strategies used to ensure credibility were: first, to allow member checks, which began with establishing structural coherence, i.e. all data were tested to ensure that there is no internal conflict or inconsistencies; second, establishing referential adequacy, i.e. testing all the analysis and interpretation against documents and records that were used during data collection; finally, the analyzed and interpreted data was sent to participants requesting them to evaluate the interpretations made by the researcher and to suggest changes if they are unhappy with the interpretation made by the (Guba, 1981). Data saturation also improved the credibility of the results (Bryman, 2001).

2. *Transferability*: This was to ensure that the results obtained from this study can be applied to different contexts (Shenton, 2004). Considering that ecological validity is the main concept of this study, a description of the methodology and the context of the study was conducted which will allow transfer of the findings from this study to other similar contexts i.e. resource constrained country (Guba, 1981). Perhaps the participation of rehabilitation professionals from diverse fields like psychiatry and speech-language pathology facilitates generalization of the results of the present study on ecological validity to other fields using TR.
3. *Dependability*: According to Bitsch (2005), dependability refers to “the stability of findings over time” (p. 86). The methodology of this study needed to be repeatable, well designed and strategic to achieve dependability. The semi structured interview schedules were added as an appendix to ensure that the study can be repeated. Stepwise replication strategy was performed where two researchers analyze the same

data separately and compared the results (Chilisa & Preece, 2005). Code-recode strategy was used wherein the researcher coded the same data twice by giving at least one weeks' gestation period between each coding. The results from the two coding are compared to see if the results are the same or different (Chilisa & Preece, 2005). This helps the researcher to understand deeply the patterns of the data; and improve the knowing of the participants narrations.

4. *Confirmability*: This ensured that the findings represented the participants own views and that the results were free from the biases of the researcher (Shenton, 2004). The transcripts were analysed by another independent researcher. A comparison between the transcription of the researcher and a research assistant, showed high agreement. High agreement between the two set reflects on the confirmability of the results.

3.3 Phase Three- Effectiveness of an ecologically valid TR for neurogenic dysphagia assessment

After the completion of the phase two study which helped the researcher to identify the variables that establish ecological validity and affect the effectiveness of TR, it led to phase three (chapter five). Technology related, context related, clinician related and some patient related factors that were identified were incorporated in phase three to establish ecological validity of TR. The aims and objectives of study 2 are listed below. This is presented as manuscript three in chapter five.

Ethics approval was obtained for this study from the University of KwaZulu-Natal Biomedical Ethics Research Committee (BREC) with the reference number BFC452/15

(Appendix 1) and from NIMHANS ethics committee, in India with the reference number NIMH/DO/Ethics Sub-committee/30//2016 (Appendix 2).

3.3.1 Study aim and objectives

The main aim of study two was to investigate the effectiveness of an ecologically valid TR in the assessment and primary management of neurogenic dysphagia in India. The objectives of study two were as follows:

1. To compare the results obtained using CSE through TR mode and face to face mode with the intention to examine if the scores are reliable
2. To examine and explain the effect of variables that influence ecological validity; that is, to see the effect of patient, clinician, technology and context related variables on the effectiveness of TR in the assessment and primary management of neurogenic dysphagia.

3.3.2 Study design

The study followed a mixed method design with a concurrent triangulation design that used both quantitative and qualitative elements (Creswell, 2013; Creswell & Clark, 2011). The qualitative analysis was used to enhance and support the quantitative data. The strengths of this type of design is that it can help to generalize the results and validate an instrument. The results from the CSE were subjected to a quantitative data analysis, whereas the study used a case study design (Denzin & Lincoln, 1994) to describe the variables that may affect the effectiveness of TR, which is not just technology dependent.

3.3.3 Study method

Direct observation method was used to conduct the clinical swallow evaluation, wherein the TR-SLP observed the responses of the SPs to the various commands, food and liquid trials. This method helped to observe the swallowing function of the SPs in detail in a clinical setting. It helped to find the occurrence or non-occurrence of features of swallowing and how frequently this happens (Shaughnessy & Zechmeister, 1985). The main categories being assessed in the CSE were oral motor assessment, tongue function, liquid trial, food trial, dysphagia severity rating and diet recommendation. The SPs were able to portray the oral motor assessment, tongue function, liquid trial and food trial just as a real dysphagia patient.

3.3.4 Data collection tool

The ‘Clinical swallow evaluation (CSE) proforma’ (Appendix 5) developed by Sharma (2012) was used for dysphagia assessment. The terminology relating to food textures and liquid consistencies were modified to make them consistent with the diet framework provided by the International Dysphagia Diet Standardization Initiative (IDDSI). Skype® was used as the TR mode for the researcher to access the participants, since it was identified as the most commonly used internet application to provide TR services in India. Consent was sought from Sharma to modify and use the CSE tool for the current study.

3.3.5 Study participants and sampling

Four participants were involved in the assessment task. They were: one SLP in Abu Dhabi (United Arab Emirates) using TR (TR-SLP); one face-to-face SLP (FTF-SLP) in India;

the simulated patient (SP) and an assistant in the room; one SP in an outpatient clinic set up in India. Consent was obtained from the SPs (Appendix 6) and the FTF-SLP (Appendix 7).

The FTF-SLP had twenty plus years of experience in the intervention of dysphagia and has worked in acute inpatient and outpatient rehabilitation set ups. Hence her vast experience and knowledge was relied on for the CSE, which included dysphagia assessment, dysphagia outcome severity rating, diet recommendation and further recommendation, to ensure that understanding of each range of severity was similar to the TR-SLP's. Three clinicians, each with over five years of experience in managing patients with dysphagia were identified through purposive sampling. They have been working in an outpatient rehabilitation set up. They acted as SPs with specific oromotor and swallowing problems. A SP is a patient scenario that is acted out by a healthy individual in such a way as to realistically represent a real patient with specific symptoms or problems (Battles, Wilkinson, & Lee, 2004). SPs, who were in India were used in this study to eliminate the risk of having undetected aspiration that occur in a real patient during the trials. As explained in chapter one, technology related, context related and to a certain extent, patient related factors were incorporated to establish the ecological validity of TR, even though SPs have been used. This is considering that the study was conducted in a context ripe with issues related to technical deficits, skills deficits and contextual issues in a resource constrained country such as India. This will be discussed further in detail in chapter five. An external SLP was availed for the purpose of training the SPs to avoid the bias factor, who were trained in all four scenarios of dysphagia. She had over ten years of experience in dysphagia. The external SLP provided a two hour training to all the SPs to portray the various scenarios of patients with dysphagia. Further instructions and advice were given based on the simulated patients' performance before they were assessed by the TR-SLP and FTF-SLP. The case details were provided only

to the SP and no information other than age, sex and a brief medical history was provided to the assessing TR-SLP and FTF-SLP.

3.3.6 Study location

The researcher who was the telerehabilitation-SLP (TR-SLP) was in Abu Dhabi (United Arab Emirates), the face-to-face SLP (FTF-SLP) was present in India, the simulated patient (SP) and an assistant was present in the room with the SP in an outpatient clinic set up, who were also in India.

3.3.7 Data collection process

Direct observation was the strategy to obtain data. Three SLPs agreed to participate as simulated patients and one agreed to be the FTF-SLP. The SPs were asked to portray any case scenario of their choice among the five scenarios of normal swallow, mild dysphagia, mild-moderate dysphagia, moderate dysphagia, moderately-severe dysphagia and severe dysphagia. Prior to each assessment, a two hour training course designed to help the SPs play their roles, was delivered with the help of an external SLP to avoid bias by the researcher. During the training, they were informed about the simulation scenarios and CSE. They were given details of the diagnosis, general medical state, oro-motor function, aspiration risk of certain food and fluid consistencies and overall dysphagia severity. The three SLPs were trained in all six scenarios. Further instructions and advice were given based on the SP's performance. Information other than age, sex and a brief medical history was not provided to the assessing TR-SLP and FTF-SLP. When one SP was being assessed, another SP served as the assistant in the room to follow the instructions provided by the TR-SLP. The FTF-SP,

who was with the patient, observed the CSE. He/she also completed the CSE assessment proforma independent of TR-SLP.

The researcher, who led the CSE, was the TR-SLP in Abu Dhabi (United Arab Emirates) with Skype® being used as the TR tool. The FTF-SLP was present in the room with the SP in India and did the CSE independent of the TR-SLP to establish the concurrent feasibility of the TR assessment compared to the standard clinical assessment environment. The TR-SLP used a notebook computer and the SP used a tablet computer on which Skype® was loaded for the assessments. The FTF-SLP had freedom of movement that allowed close up views and the ability to touch the patient to assess oro-motor muscle strength. The assistant's role was to position the patient directly in front of the computer. During the assessment, the assistant aided the TR-SLP with the oro-motor, food and fluid trials and repositioned the computer camera. Diagnostic and management decisions were not verbalized amongst the FTF-SLP and TR-SLP, during the assessment, so as not to confound their respective decisions.

3.3.8 Data analysis

The effectiveness of TR for the assessment and primary management of neurogenic dysphagia was done by calculating the inter-rater reliability using the percentage exact agreement (PEA) and Cohen's Kappa (k) between the scores of the TR-SLP and FTF-SLP on the major categories of the CSE, which were oral motor assessment, tongue function, fluid assessment, food assessment, severity rating and diet recommendation, for the quantitative analysis which helped to establish the effectiveness of TR in neurogenic dysphagia assessment.

The results were also presented as a qualitative case study with each case being reviewed under the main themes of patient, clinician, technology and context related factors. The aim of this qualitative study was to describe the reasons for different scores on CSE.

3.3.9 Reliability and validity of the study

Joppe (2000) defines reliability as the extent to which results are consistent over time. An accurate representation of the total population under study is referred to as reliability and if the results of a study can be reproduced under a similar methodology, then the research instrument is reliable (p. 1). Hence, reliability in this study is the ability of the CSE to produce similar results when carried out through TR or FTF mode. The reliability of using TR mode to assess and conduct primary management of neurogenic dysphagia was investigated during the data analysis stage of this phase, by using inter-rater reliability scoring.

Joppe (2000) defined validity as the ability of the research instrument to truly measure what it really intended to do. The CSE of Sharma (2012) has been reported to be a valid tool for the assessment and primary management of neurogenic dysphagia. TR for the assessment and primary management of dysphagia has been found to be a valid tool in studies conducted in the economically developed countries. Its effectiveness is being investigated in this phase.

A query regarding selection bias can arise in this phase when considering the use of SP since they are normal people portraying neurogenic dysphagia and whether the researcher's knowledge of the severity of dysphagia could have biased the scoring. Selection

bias occurs when the participants selected for the study do not represent the real population in question. However, the need to select SP as participants were explained theoretically and methodologically in figure 1.1 in chapter one. However, to avoid bias, the training of the SP to portray a case with neurogenic dysphagia was conducted by an external SLP who was experienced in the management of dysphagia. Six case scenarios were presented and the SP could choose to portray any one of them and only 4 case scenarios were portrayed to the researcher (TR-SLP) and the FTF- SLP. TR-SLP and FTF-SLP were given information only regarding the age, sex and a brief medical history of the SP.

Chapter Four

Ecological Validity of TR in Resource Constrained Countries

4.1 Overview of the chapter

Literature review in phase one of the study indicated that TR is a feasible method for the intervention of dysphagia. It also aided in identifying the factors that could affect the ecological validity of TR which could be attributed to its effectiveness when implementing it in a resource constrained country. This is considering that the situation in a real life environment is far from perfect from that of a controlled one. The influencing factors could be those related to patient, clinician, technology and context. However, these factors needed to be explored in greater detail to ensure that the TR implementation for the intervention of neurogenic dysphagia is contextually responsive and holistic, based on the paradigm shift to a constructivist one, ontologically, epistemologically and methodologically.

It was clear that there is a dearth of dysphagia experienced SLPs in resource constrained countries like India. This is clearly an unacceptable situation considering the increase in the prevalence of neurogenic dysphagia in these countries. TR can be a solution to meet the increasing demand for services relating to intervention of dysphagia. However, as identified in the literature review, past research has come mainly from the economically developed countries and before implementation of such new technology in a resource constrained country like India, the ecological validity of TR and its effectiveness to be established.

Though telemedicine has been used in resource constrained countries for more than a decade, not much literature is available on the use of TR in such settings. Hence, this phase aimed at investigating the ecological validity of TR in a resource constrained country such as India. The objectives for this phase are as below:

- i. To investigate the current status of TR in India through an understanding of the knowledge and attitude of TR personnel.
- ii. To identify the variables that affect the ecological validity of TR in India based on the practice of the TR personnel.

A manuscript, reproduced below, will be submitted to the Journal of Telemedicine and Telecare.

4.2 Manuscript Two

Investigating Ecological Validity through Knowledge, Attitude and Practice of Telerehabilitation in India

Abstract

As telerehabilitation (TR) is a novel method of service delivery with most research having been conducted in economically developed countries, the various factors that affect its ecological validity should be identified when importing this idea to resource constrained countries, such as India. In depth semi structured interviews were used to investigate the knowledge, attitude and practice of TR personnel in India. The participants reported satisfactory knowledge of other professionals and patients or caregivers regarding TR in India. Every participant had a positive attitude towards it. Practice identified the variables affecting the ecological validity as poor internet and electricity connection, availability of computer and related devices, knowledge of computer use by patient, caregiver and on site clinician, intervention skills of on-site clinician, cause and severity of the disorder, and other comorbidities of patients.

Key words: ecological validity, effectiveness, resource constrained country, real life settings, TR

Introduction

Telerehabilitation (TR) constitutes a very small part of the literature on telemedicine (Russel, 2007), with very few studies being reported in India (Rao, Iyer & Anap, 2012). The literature indicates that while telemedicine, which started in 2001 in India, offers great opportunities to health care in general and for rehabilitation services (World Health Organization, 2010), it could be particularly beneficial for resource constrained countries, where access to basic health care is compromised by lack of services and skilled professionals care (Mars, 2011). Providing populations in underserved countries with the means to access rehabilitation services has the potential to help meet previously unmet needs (Patnaik & Patnaik, 2015) and positively impact health services (Ganapathy, 2004). With an increase in the various disorders such as cerebro vascular accidents, traumatic brain injury, global developmental delays in paediatrics, etc. that require rehabilitation interventions like physiotherapy, occupational therapy, speech language pathology and the like in India, and considering their dearth, a new method such as TR need to be considered for the intervention of such patients.

Based on the KAP framework (Kaliyaperumal, 2004; Launiala & Kulmala, 2006; Pelto & Pelto, 1997; Richards et. al, 2005; World Health Organization, 2008; Yoder, 1997) the knowledge, attitude and practice of TR needed to be investigated during its implementation, due to it being a new intervention system, specifically into resource constrained country, where the challenges to its use may not only be technology related. Knowledge means the ability of pursuing and using information, and understanding, learning, experience and identifying the studying technologies (Badran, 1995). It is the capacity to acquire, retain and use information; a mixture of comprehension, experience, discernment

and skill. The possession of knowledge requires a concept about the object and a perception of the concept. Education helps to acquire knowledge. Knowledge in this context refers to the knowledge about the TR, how to use it, its benefits and disadvantages. Thus, the question that arises here is if the clinicians in India have been educated about TR.

Attitude indicates the disposition of making reactions via some ways in any situation; observing and explaining events based on certain predisposition or organizing ideas into coherent and inter-related views (Badran, 1995). Practice indicates what knowledge and habit work together. It is the application of rules and knowledge that leads to action. Good practice is the art that is associated to the improvement of knowledge and is conducted in an ethical manner (WHO, 2008). Attitude refers to the attitude of clinicians and patients towards using TR for any intervention. Practice refers to the current practice of TR in a resource constrained country. Variations in practice may occur based on various geographical, socio-economic, political factors. There also needs to be an understanding about the factors that affect the ecological validity, implementation and range of TR practice in India.

As reported by Mars (2011), to successfully implement TR in a resource constrained country, there needs to be awareness of TR and its scope of practice. As in many such countries, the academic teaching departments are largely unaware of TR. Despite increased reporting about TR research in the literature, many clinicians are still not using it, which may be due to the lack of knowledge, technical skills, understanding or its accessibility (Ward & Burns, 2014). Mars (2011) noted that clinicians who have used videoconferencing, Skype®, email and telephony for work have been driven by local need and the availability of infrastructure. Only a small percentage of rehabilitation professionals in the USA use TR for regular interventions due to issues such as limited access to the internet at work and poor

technical support (Ward & Burns, 2014), which is likely to be even less favourable in India. While TR appears to be a possible solution to overcoming the short comings, it has not been widely used in India, making it necessary for it to be either developed or imported. This raises the issues as to whether the TR systems used in developed countries, as reported in studies conducted by Sharma (2012) and Ward and Burns (2014) can be imported to a country such as India, while ignoring the lack of ecological validity in that setting or can instant messaging applications can be used.

Ecological validity is a form of external validity, the former referring to the extent to which findings can be generalized to the settings and people in all societies, and the latter to the overall extent to which findings can be generalized across people, places and time (Roy & Kathleen, 2007). The term ecological validity was applied to the environmental context of psychology research, the impact the setting had on the study, being questioned by Brunswick (1942) and Lewin (1943) (Schmuckler, 2001). To obtain results that are ecologically valid, participants must be studied in the richness of their natural settings. The concept of ecological validity refers most narrowly to the degree to which the definition of a unit of analysis reflects the way that unit is defined in real life by people or natural features (Perkins, Florin, Rich, Wandersman & Chavis, 1990). Ecological validity has usually been studied in economically developed countries to establish if the methods, materials and setting of a study approximate the real world that is being examined (Schmuckler, 2001). Ecological validity is generally regarded as the degree to which results obtained in controlled experimental conditions are related to those obtained in natural environments (Denzin & Lincoln, 1994). Validity does not apply to the test itself, but to the inferences that are drawn from the test (Heinrichs, 1990; Franzen & Arnett, 1997). Therefore, tests that have adequate diagnostic

validity do not necessarily have adequate ecological validity, which can be influenced by various factors, this also applying to the use of TR.

This study aimed to investigating the ecological validity of TR in a resource constrained country such as India using a formulative exploratory research design, which helps to explore ideas and insights into a new field and usually deliver new information about the topic for research (Creswell & Plano Clark, 2011). It helps to fulfill the researcher's curiosity and need for greater understanding, to test the feasibility of starting a more in-depth study, and to develop the methods to be used in any following research projects.

Method

Ethics approval was obtained from the University of KwaZulu-Natal Biomedical Ethics Research Committee (BREC) (reference No. BFC452/15) (Appendix 1) and from the Indian NIMHANS ethics committee, (reference No. NIMH/DO/Ethics Subcommittee/30//2016) (Appendix 2).

Exclusively recruiting rehabilitation personnel like speech language pathologists in India who were using TR was not possible due to the limited number and very few consenting to participate, which resulted in local TR personnel such as doctors also being included. Purposive sampling of two psychiatrists and six speech language pathologists were recruited. Their demographic details are provided in table 4.1. Clinicians who had been providing TR for less than one year were excluded owing to their lack of experience. Purposeful sampling was used to identify individuals or groups of individuals who are especially knowledgeable about or experienced with a phenomenon of interest (Patton, 2002;

Creswell & Plano Clark, 2011). Informed consent was obtained, after which each interview lasted an hour using Skype®, as the interviewer was in Abu Dhabi (United Arab Emirates) and the interviewees were in India. Interviews were done in English and were audio recorded.

Table 4.1: Demographic details of the study participants

Participant	Gender	Age (years)	Profession
A	Male	45	Psychiatrist
B	Male	40	Psychiatrist
C	Female	32	SLP
D	Female	58	SLP
E	Female	23	SLP
F	Female	22	SLP
G	Female	23	SLP
H	Female	25	SLP

The semi structured interview guide, based on the KAP model, consisted of two levels of questions: main themes and follow up questions. The participants were encouraged to speak freely about their knowledge, attitudes and practices (Åstedt-Kurki & Heikkinen, 1994). These questions were about issues that were familiar to the participant yet central to the study subject (Whiting, 2008). The transcripts were entered on NVIVO 1.0, a computer software package, with thematic analysis resulting in several themes and general findings emerging using coding, categorizing, delineating and connecting them (Boeijie, 2002). The transcripts were analyzed and compared by two researchers under the main categories of knowledge, attitude and practice. Key findings were reported for each of the three categories' main theme, these being illustrated by appropriate quotes.

Credibility of the study was established by member checks, referential adequacy and data saturation. Transferability was ensured with a description of the methodology and the context of the study was conducted which will allow transfer of the findings from this study to other similar contexts i.e. resource constrained country (Guba, 1981). Participation of rehabilitation professionals such as psychiatrists, other than SLP aided transferability of the findings to all other fields using TR. Dependability was established by providing the semi structured interview schedules as an appendix to ensure that the study can be repeated. Code-recode strategy was used. The results from the two coding are compared to see if the results are the same or different (Chilisa & Preece, 2005). This helps the researcher to understand deeply the patterns of the data; and improve the knowing of the participants narrations. The transcripts were analysed by another independent researcher. A comparison between the transcription of the researcher and a research assistant, showed high agreement. High agreement between the two set reflects on the confirmability of the results.

Results and Discussion

Eight people participated in the study, of whom two were psychiatrists and six were speech language pathologists. The results are divided into three main categories of knowledge, attitudes and practices, with further sub categories under each and themes were identified. This has been illustrated in figures 4.1, 4.2 and 4.3.

Knowledge regarding TR in India

Two sub categories emerged under the category knowledge, these being the current status of TR in India and within the organization, as depicted in figure 4.1. The participants' knowledge regarding TR in India provided an insight into its status. Having started in 2001, TR is more than a decade old in India, i.e. fifteen years. In the initial years, though, TR was not accessible to the public. It was mainly accessed by the doctors for consultations amongst themselves. Patients accessing health services in the public sector do not have access to TR, unlike the private sector, where hospitals make use of technology. It has become accessible to the general population for direct interventions during the last 10 years in India, as stated by the SLPs from a pioneer institute in India. The few specialities using TR in India were reported to be radiology, psychiatry and surgery. However, there are no state or central government level rules or regulations to guide tele services in India, which results in each organization having its own. Holla et. al (2013) states that currently there no laws to regulate the TR practice in India.

The personnel reported that TR is reportedly widely accepted by patients and their caregivers because it provides quick and easy access to professionals. The study conducted regarding the use of TR in India indicated that there has been limited implementation despite TR being known to be very efficient in terms of time, money and effort.

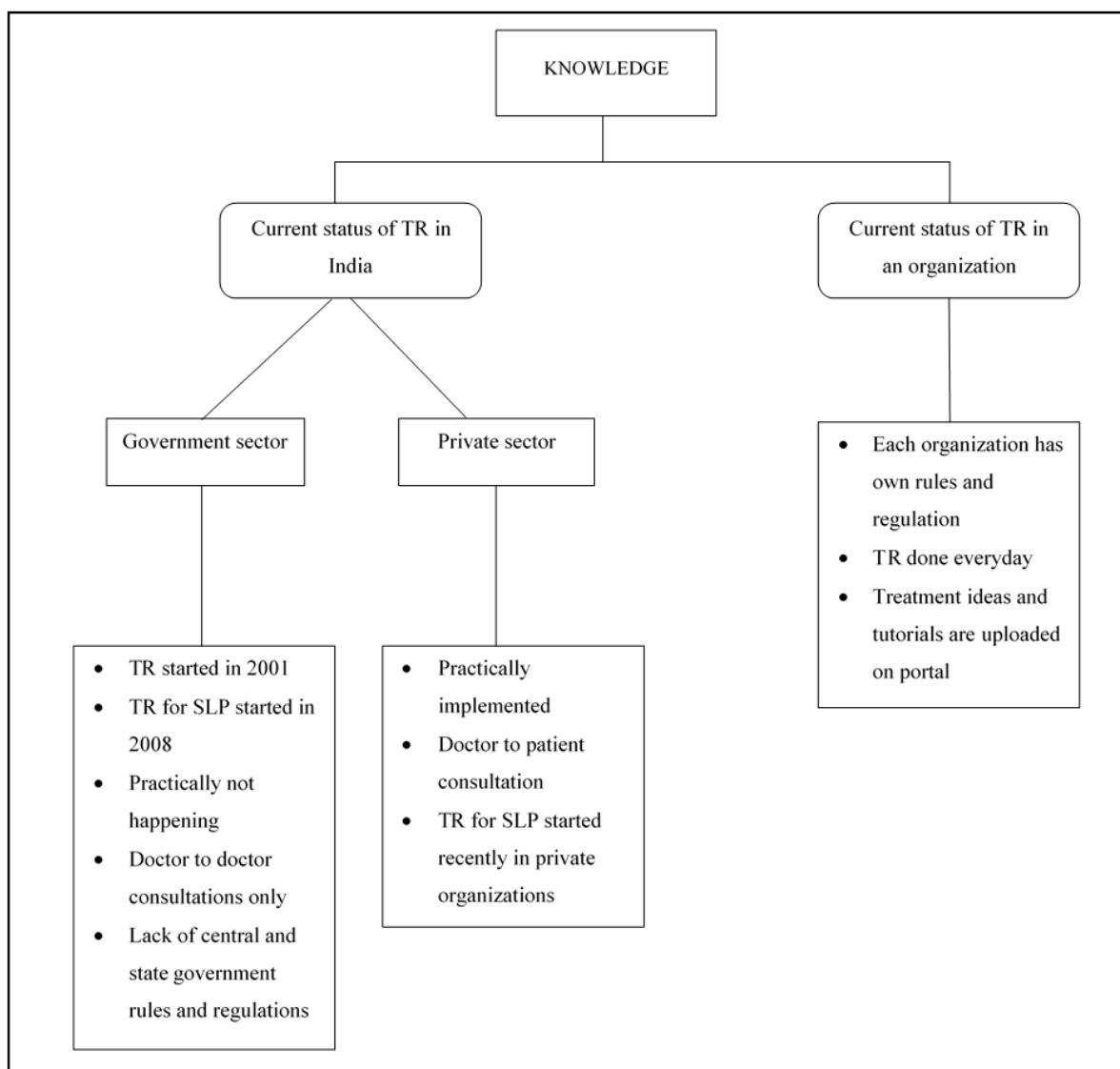


Figure 4.1: Knowledge regarding TR in India

Sub category 1: Current status of TR in the government sector. Although telemedicine has been in use in India since 2001, it has not received the expected support in the government sector hospitals due to various constraints such as lack of funding and changing political agendas. The participants noted that TR has considerable potential in India to address the treatment gaps, but that while this is theoretically feasible, attempts to implement it in public sector facilities have not been very successful. Participant C (semi structured interview 3) stated that India has come up with good research regarding TR services, but unfortunately are unable to implement in real life situations. This is associated

with the appropriate funding available for research projects and not so for its real life implementation. TR is mainly used for doctor to doctor consultations, and is being used in only one academic institute done speech language pathology services, as stated by participant D (semi structured interview 4).

Sub category 2: Current status of TR in private sector. The TR personnel stated that the technology has been well supported in private sector hospitals due to adequate

In India, there is a lot of scope for telemedicine, theoretically. But practically it's not happening. That is what the government of India is working on. [Participant B semi structured interview 2]

funding, which contributes to generating a good income as there is doctor to patient TR consultations. TR for speech language therapy is mainly being provided by SLPs working in private facilities with three being known to the participants in this study. Each organization has its own set rules and regulations for using TR, with most participants indicated that the government needs to develop rules and regulations for use throughout the country, to avoid confusion or misunderstanding regarding the ethical obligations associated with the technology.

“We had the symposium of digital mental health, where many people asked regarding the rules and regulations of teleconsultation, which we don’t have at present in India”

[Participant B semi structured interview 2].

“an international conference on telerehabilitation by the TR society of the USA and the TR society of India. Even I think they are at loggerheads regarding the policies, they are also not very clear about the terms and conditions.” [Participant D semi structured interview 4].

Attitude towards TR in India

Attitude of professionals towards TR in India, as illustrated in figure 4.2, can be discussed in detail under the below sub categories, with themes identified and discussed in detail.

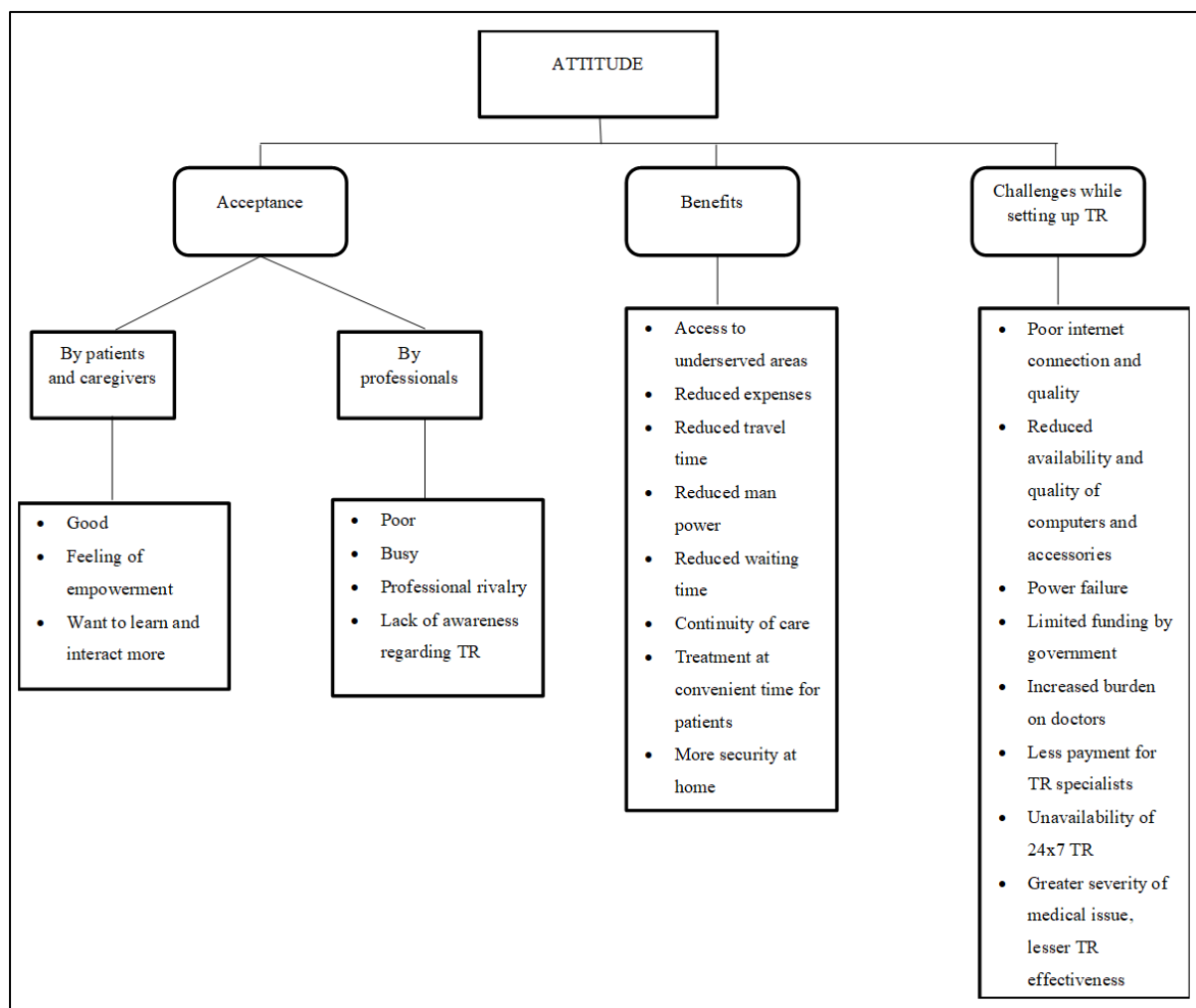


Figure 4.2: Attitude of TR personnel in India towards TR

Sub category 1: Acceptance of TR by professionals in India. The TR personnel thought that service provision through TR was not widely accepted by health professionals in India. As stated by Math, Moirangthem and Kumar (2015), one main reason was that a physician would not want to liaise with another, which may be due to professional rivalry.

“For example, a physician in a district hospital wants to talk to a neurologist here or a paediatrician wanting to talk to a paediatric neurologist. A specialist would not like to take that kind of an advice.” [Participant C semi structured interview 3]

Another reason was that the doctors in the government sector are already burdened with their own large number of face to face patients, and therefore have no time to provide TR services. India has one government physician for every 11528 people and one nurse for every 483 people, figures from a report on the country’s health sector have shown (Bagcchi, 2015). This is associated with the dearth of doctors working in the government sector hospitals, which is also due to their poor remuneration. Most doctors in the government sector hospitals would welcome the use of TR if it would reduce their work load and travel time to the various district hospitals or primary health care centres at which they provide services. However, TR is well accepted by the doctors in the private sector, since the mentioned reasons may not be affecting their services. They operate under different circumstances to those in the public sector, with better salaries and lower patient loads.

Most referring physicians were unaware of the use of TR, especially for speech language pathology services in India, which is a barrier to its growing use. For those who are aware of it, TR for speech language pathology services is well accepted by them, with many showing an interest in referring patients for the same.

“In fact, last week I had been to an international conference and the person was so amazed and said that they were totally unaware that such a service is available. So, it’s our fault and their poor knowledge. We have failed to publicize or their poor knowledge!” [Participant D semi structured interview 4]

Sub category 2: Acceptance of TR by patients or caregivers in India. TR is welcomed by patient and/or their caregivers in India as it gives them access to health care services that are not locally available, and which they might not otherwise have benefited from. As unanimously agreed by the participants, there is a dearth of doctors in the government sector hospitals and speech language pathologists in India in general. This new mode of service provides easy access to the professionals from any corner of the country. Parents feel empowered while doing speech language therapy through TR and want to learn and interact more during the sessions. The participants of this study have informed that they welcome TR as it gives them access to health care services that are not otherwise not available and it is cost effective.

“So majorly it’s the mothers who want to learn and they want to be in-charge of doing therapy for their children. We have many parents who call us and ask about us. But who sign up for real therapy are those who want to do and have that time and efforts to give that dedication.” [Participant A semi structured interview 1]

“Because it is convenient for them. It reduces expenses. They don’t have to wait for long to see a doctor. So, its acceptance is definitely much better.” [Participant B semi structured interview 2]

As stated by participant A, TR ensures greater parent empowerment and it is an unanticipated advantage. This enables greater understanding and better transfer, generalisation and prognosis of the patient. Previous studies done by Ward et. al (2009), Schein et. al (2010), Tousignant et. al (2011), Sharma et. al (2013), etc. to name a few, have reported high patient/caregiver satisfaction in the use of TR, which subsequently led to acceptance.

Sub category 3: Benefits of TR in India. The main benefit stated by all the participants is that treatment can now be accessed from even patients' homes or primary health care centres in remote areas of India. As stated by participant B, the Prime Minister of India is now working towards a 'digital India', which is a campaign, launched by the government to ensure that government services are made available to citizens electronically. This is done by improved online infrastructure and increasing internet connectivity or by making the country digitally empowered in the field of technology, with three core components of digital infrastructure, delivery of services digitally and digital literacy. (Prakash, 2015). It includes plans to connect rural areas with high-speed internet networks, which will make TR possible for people throughout the country.

In addition, treatment through this new mode has now become cost effective. TR helps save money by reducing the need for patients to travel to the hospitals to meet a doctor or to a centre for speech language therapy, physiotherapy or occupational therapy services. For patients who experience constraints that affect their ability to travel, services available through TR save on travel expense and time. This can be considered advantageous for

patients from remote areas in India, who may have to travel a few hours to reach a main city to access various therapy services.

“Parents find it hard to make it to the therapy appointments because they have to go for speech, they have to go for occupational therapy, they have to go physiotherapy, they have to so many other allied services and they are all in different place. So, reaching them and following up at home gets very overwhelming for certain parents. For them telepractice is helpful.” [Participant A semi structured interview 1]

Another benefit indicated by the speech language pathologists regarding using TR was the continuity of care the technology provided. The professional can access the patient from where he/she is and vice versa, if they are moving places within the country or outside the country. A change in health professionals at a centre will not affect the therapy services provided when they are accessed through TR, unlike in a face to face setting. In addition, patients and caregivers feel more secured when they are availing therapy services at home, since they can witness the happenings for themselves and do not have to travel long distances. Participant A reported that paediatric patients with developmental language disorders such as cerebral palsy improved when speech language therapy services were provided through TR.

Sub category 4: Challenges faced during setting up TR. A common challenge stated by all participants was the lack of funding by the state or central government to set up TR in government organizations. There were also major concerns regarding poor internet connectivity and the use of old computers or related accessories, which made using TR difficult. Another challenge was the lack of available IT professional or a biomedical

professional to assist with setting up TR in organizations, the low salaries of government employees resulting in such skilled persons seeing employment in the private sector as beneficial.

The severity of a patient's condition was also stated as a factor that affects the effectiveness of TR, with all the participants indicating that they prefer face to face with the more severe cases. In the case of speech language pathologists, paediatric cases with attention deficit or poor eye contact posed a challenge using TR, with participant D (semi structured interview 4) suggesting the use of a trained aide at the site of the patient to assist in such situations. Participant C suggested the inclusion of an onsite junior doctor or a general physician to be trained to aid the TR physicians, which could be a novel thought to be considered for future research and implementation in resource constrained country.

Practice of TR in India

Participants' responses regarding their daily practice of TR provided insight into the factors that can influence the ecological validity of TR and thus its effectiveness, this being divided into five themes, as indicated in Figure 4.3.

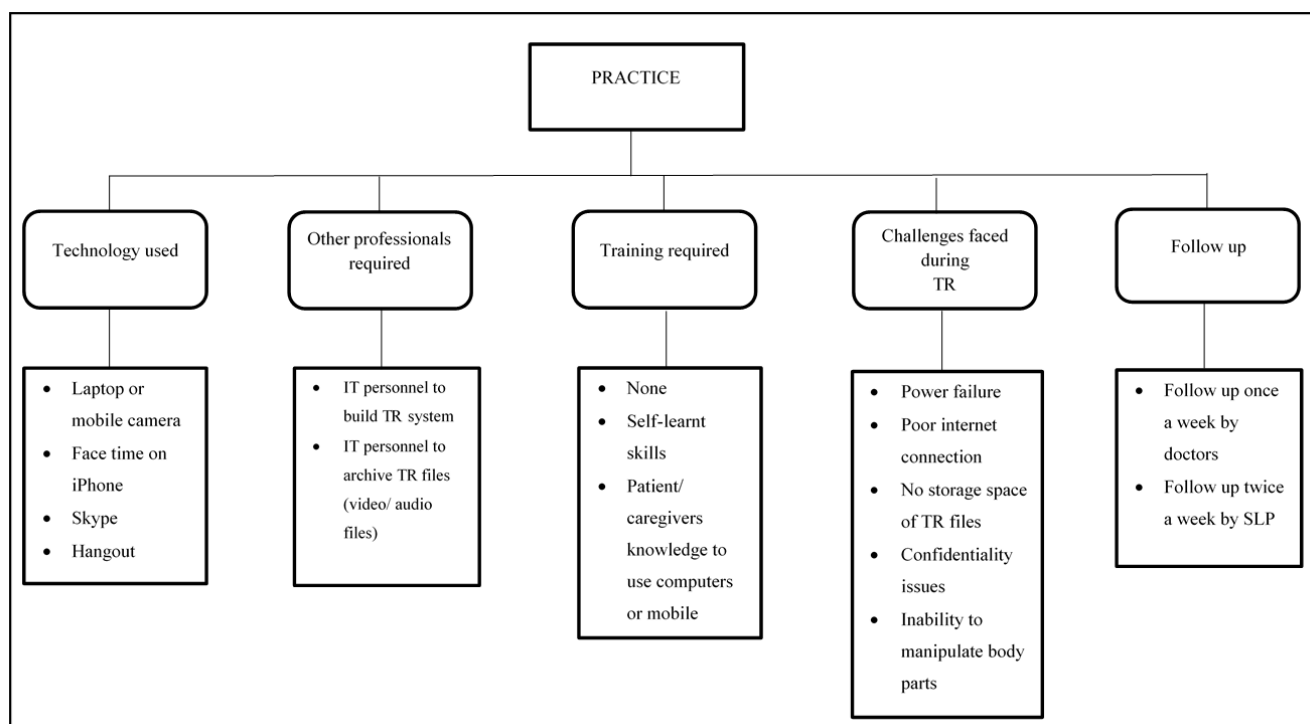


Figure 4.3: Practice of TR in India

Sub category 1: Technology used. Skype® was the most commonly used internet application used by most participants for their tele-services. Participant A reported that she also used other applications such as Hangout ® and face time on iPhone®. All participants used the inbuilt camera in the laptop or personal computer or the mobile phone.

Sub category 2: Other professionals required. Information technology (IT) personnel are required during or after a tele consultation, to solve problems that happen with the system during the session and for later storage of the videos. As stated by participant E (semi structured interview 4), while they can also help to retrieve these videos for later use, their lack of availability made it difficult to assist with the system during a tele-session, which results in the end users having to solve the problems by themselves.

Sub category 3: Training required. All the participants reported that no specific training in TR was obtained before starting these services in their respective organizations having been self-taught skills and learnt through trial, error and improvisation. Holla et. al (2013) reported in their study that 52% technicians reported they have never undergone training and the rest had undergone training once. As stated by participant D (semi structured interview 4), all TR service providers in India may not have received any formal training

“We shared and learned. I would say often it was a trial and error.” [Participant F semi structured interview 4]

before starting to use it, suggesting that it is not too complicated to exclude untrained persons.

The instant messaging applications used by the participants did not require any specific training. The participants noted that patients or caregivers could use them effectively and needed instructions to place the camera in a particular way for good visual clarity during the tele service.

Sub category 4: Challenges faced during TR. The most common issues faced during TR sessions in India are power failures, low bandwidth and poor internet connectivity, with power outages occurring at least once a day. While remote TR personnel may have good internet connectivity and no power failures, this may not be the case for the patient. Weather conditions such as heavy rains, which are very common in many parts of India, can disconnect power and internet connection. This is compounded by old devices, such as the laptop or a personal computer, which can hinder the audio-visual clarity at both ends. The TR personnel preferred the use of notebook or personal computers to mobile phones, as they

provide clearer videos and audio output. While the use of mobile phones or tablets during TR can hinder effective communication, most of India's population cannot afford personal computers or laptops, with many having old computers that cannot accommodate modern communication software and takes long time to boot and start. Most household in India use computers or laptops for an average of 5.94 years (Joseph, 2007). This result in the use of mobile phones to access tele-services, the situation being the same in the primary health care centres that are connected to the major hospitals that provide TR services, which makes communication difficult, even for those who would like to use the technology. In addition, the computer literacy of patients and caregivers can also pose as a challenge to initiating the communication as well as during the TR session.

“it should not happen that you have to log onto your desktop computer which is God's number of years old and it will take 5-20 minutes to act.” [Participant C semi structured interview 3]

A commonly raised obstacle by the participants A (semi structured interview 1), G (semi structured interview 4) and H (semi structured interview 4), who were speech language pathologists, was the challenge of providing language therapy to children who have severe autism or attention deficit hyperactive disorders in addition to poor eye contact. Similar findings were reported in studies conducted in developed countries (Hill, et. al, 2009, Ward, et. al, 2014). Thus, as the severity of the disorder increased, therapy through TR mode proved to be more challenging than a face to face session. Sessions need to be made creative for any paediatric cases to keep their interest going during the sessions, which can be difficult using TR where the therapist cannot physically engage with the patient. Oral motor structure manipulation is affected when required for a case, for which, a caregiver's help may be

necessary, which in turn may be affected if they are unable to follow the instructions provided.

“So I think a lot of this depended on how much or what severity of the problem of the child. We started with a child who had ADHD or very severe autism and moved into their issues with their activities and place and things like that. Those were the parents who did not find it very successful.” [Participant A semi structured interview 1]

“in certain conditions like where the clinician should manipulate the oral structures of the child or the adult for treating conditions like motor speech disorders, TR is posing a limitation” [Participant H semi structured interview 4]

Storage of the TR videos was a concern raised by participants B (semi structured interview 2), C (semi structured interview 3) and D (semi structured interview 4), who stated that these videos should be stored safely to ensure confidentiality of the patients. These videos are also required for future consultations and if possible for future research purposes. However, due to the large number of these videos, storage space becomes a problem, which needs to be addressed at both a policy and organizational level. A solution needs to be sought for this. These digital resources could be of great use for future research in India.

Sub category 5: Follow up. Follow ups after the initial assessment, is possible for the TR service providers in India. Participants A (semi structured interview 1), C (semi structured interview 3), F (semi structured interview 4) and H (semi structured interview 4) provided two sessions per week for most of their patients, this increasing when the patient's

prognosis was good. Participant A (semi structured interview 1) worked for a private organization that had other modes of follow up, such as sending emails with the home therapy activities to the parents and a Facebook® page where parents could interact and get new ideas from the speech language pathologist. Participants B (semi structured interview 2) and C (semi structured interview 3) reported that they could provide follow up session once per week for their patients.

Overall, the results obtained from the current study helped identify the factors that affect the ecological validity of the TR. Most of the factors are due to the vast geography of India, wherein majority of the population live in remote areas. Many rural areas may have poor access to the regular health care facilities, while power failures are common, even in metropolitan areas, which can affect the internet connectivity. The internet providers may not have facilities to provide uninterrupted internet to its customers.

The lack of government infrastructural support appears to be the main element influencing all the other factors that influences the ecological validity of a new intervention system such as TR. The major constraints in infrastructure could be the political and regulatory risk such as formulating central government level rules and regulations to govern TR services, which would lead to its streamlining and obstacles to access financing or funding. Hence, this amounts to the medical and non-medical infrastructural restraints scarcity of healthcare workers in the government sector and increased burden on the existing professionals, electricity and internet supply, to name a few. A clear vision regarding the future of the health care needs in India will be beneficial for the advancement and success of TR particularly for rehabilitation services in India.

Conclusion

This study provided an insight into the current situation of TR in India and helped to identify the factors that affect its ecological validity from the perspective of the professionals working in India. It detailed that TR is an effective method of service delivery in this resource constrained country, where specialised services may not be available in remote areas of the country. However, a dearth of clinicians was stated as a major challenge in the government sector hospitals, suggesting the need for public/private partnerships to address the country's growing health needs. The study also provided a more detailed conceptualization of the various factors that affect the ecological validity of TR in rehabilitation services in India. Poor internet and electricity connection, the availability of computer and related devices, knowledge of computer use by patient, caregiver and onsite clinician, intervention skills of onsite clinician, cause and severity of the disorder, other comorbidities of patients and environmental factors such as noise in a real life clinical settings and weather conditions such as heavy rains that can in turn affect the technology related factors, patient and SLP were perceived as major factors that affect the ecological validity in a country with constrained resources. The current study has identified factors that need to be addressed when implementing TR in India and suggests that strategies to overcome them must be directed at creating and supporting opportunities in resource constrained country to meet patients' needs, irrespective of location.

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4.3 Summary of the chapter

The results obtained in this phase are in consonance with those identified following the literature review, wherein the TR personnel identified patient, clinician, technology and context related factors that can affect the ecological validity of TR in a resource constrained country, which in turn will affect its effectiveness. The main concepts that emerged from this phase are resource constrained countries and real life settings that define the ecological validity and effectiveness of an intervention system or method. They are described below.

Resource constrained countries.

Effective health care interventions are underutilized in the developing and under developed world (O'Donnell, 2007) due to various resource constraints as explained below (adapted from Wyss, 2004).

- (i) *Individual level constraints:* shortage of trained or experienced health care workers (dysphagia experienced or trained SLP, in this study) and improper allocation. In the matter of the intervention of dysphagia in a resource constrained country such as India, individual level factors such as lack of hands on dysphagia training of SLP is important to be considered. This leads to poor access to effective healthcare.
- (ii) *Health service delivery level constraints:* inappropriate resource (human and infrastructural resources) allocations across geographical regions and levels of care and inadequate quality that reach the underserved.
- (iii) *Health sector level constraints:* low salary of health care workers (SLP) in resource constrained countries leads to the migration of experienced staff.

- (iv) *Social level constraints:* reduced quality of information exchange among different interest groups/professional and ministries (Wyss, 2004)), migration of experienced healthcare professional leading to delayed or improper identification of diseases or disorders (O'Donnell, 2007) play a role in the effectiveness of healthcare and occasionally this becomes a norm in some underserved areas. Low literacy rate cannot be ignored either (Konduri, Bastos, Sawyer & Reciolino, 2017). For example, the reduced success rate in childhood immunization in India can be attributed to lack of awareness of mothers of the need for immunization, benefits it brings, and lack of awareness of where to get this service (Pande & Yazbeck, 2003). Hence, similar could be the situation with respect to management of dysphagia could be similar in resource constrained countries, where the patient and the caregivers are unaware of the different services available as well as the place they are available. Recognition of illness and the potential benefits of treatment are prerequisites for health care demand.
- (v) *Political and economic level constraints:* governance and policy maker issues, lack of initiation, bureaucracy, red tape, political changes, low salary are some of the constraints faced (Mills, 2014). The formulation of centralised policies and procedures for telemedicine and TR is in the process in India. Hence, the organizations using TR currently are following their own set of rules and regulations. This calls for a strengthening of rules and regulations through legal and governmental mechanisms. Physical limitations such as climatic and geographical dispositions to diseases as well as physical environments can be unfavourable for TR service delivery.

In the light of all these factors with reference to a resource constrained country such as India, the ecological validity TR assumes greater importance. In addition, the importance of real life settings on the ecological validity of TR needs to be analysed.

Real life settings

Effectiveness of a new intervention mode such as TR needs to be explored in a real life setting since effectiveness is the extent to which planned outcomes are achieved as a result of an activity, strategy, intervention or initiative intended to achieve the desired effect, under ordinary circumstances (Singal, Higgins & Wailee, 2014; Wells, 1999). However, there are other factors that can influence the effectiveness of a new intervention mode. Some of them are explained below:

- (i) *Patient related factors*: Medical diagnosis, its severity, other comorbidities and behaviour (e. g: patient may not be co-operative or feeling unwell) on the day of intervention may also influence the effectiveness of TR.
- (ii) *Technology related factors*: technology related factors such as power failures which can occur at regular intervals (also known as load shedding) may lead to disrupted internet connections and low bandwidth and result in poor audio-visual clarity of video during TR.
- (iii) *Context related factors*: environment related factors such as weather changes (such as heavy winds and rains can cause power failures) may lead to disrupted internet connections and low bandwidth and result in poor audio-visual clarity of video during TR. The noisy and overcrowded environment in a public-sector hospital (Konduri, Bastos, Sawyer & Reciolino, 2017) in a resource constrained

country such as India cannot be overlooked for its effect on the effectiveness of TR.

Overall, it has been identified that TR is feasible in a resource constrained country such as India, even with the various factors that influence its ecological validity and effectiveness wherein effectiveness means its ability to provide the beneficial outcome in a real life setting (Gartlehner, Hansen, Nissman, Lohr & Carey, 2006). TR is being effectively implemented in India for the intervention of various disorders that require rehabilitation intervention. Considering that no study has been reported till date about the use of TR in a resource constrained country, the researcher needs to be aware of and be prepared for the influence of such extraneous factors on the effectiveness of TR when implementing it in a real life settings.

Herein, the researcher's thoughts were placed in line with 'implementation research' which can address any aspect of implementation of a service including the factors affecting it. Broadly speaking, the term implementation research describes the scientific study of the processes used in the implementation of initiatives including the context factors factors that affect these processes, hence affecting its effectiveness (Peters, Tran & Adam, 2013). Implementation research may focus on issues such as: identifying common implementation problems; understanding the factors that hinder or facilitate access to health interventions; developing and testing solutions to tackle implementation barriers either within a specific context or across a range of environments; and determining the best way to introduce innovations into a health system, or to promote their large scale use and sustainability. This was explained in chapter one, wherein the researcher explained the continuum of clinical evidence (Campbell et. al, 2000; Craig et. al, 2008). Proof of concept, as explained by Peters,

Tran & Adam (2013), regarding the feasibility of TR in the intervention of dysphagia has been propounded in past research. Hence, the researcher needed to move to the next stage, i.e. proof of implementation to identify the way TR works in real life settings. However, this could be examined only in the context of a partially controlled intervention mode with only simulated patients in real life outpatient clinic settings.

The results obtained from this phase generally support the need for a paradigm shift from positivist to constructivist view, wherein TR for neurogenic dysphagia assessment and primary management needs to be investigated in real life settings. With the outcomes from this phase, as well as based on the conceptual framework developed in phase one (chapter two), some of the factors were included in phase three. The devices and technology used for TR, the current internet speed available in the study location, materials used for the CSE and real-life outpatient clinical settings were incorporated to establish the ecological validity of TR. Its effectiveness was then investigated, which will be explained in detail in chapter five.

Chapter Five

Effectiveness of an Ecological Valid TR for Neurogenic Dysphagia Assessment

5.1 Overview of the chapter

The premise for this study stemmed from the need for the intervention of neurogenic dysphagia in a resource constrained country, where there is a dearth of dysphagia experienced SLP. The researcher identified that TR can be a possible solution to meet this increasing need. The literature review identified that TR was a feasible method for the intervention of dysphagia. However, the results were applicable for only for the economically developed countries and studies were conducted in controlled settings. Thus, the ecological validity and effectiveness of TR for the intervention of dysphagia were challenged. A paradigm shift from a positivist to a constructivist view was necessary when considering using TR in real life settings in resource constrained country, such as India.

The in depth semi structured interviews aided in identifying the factors that could affect the ecological validity and hence, the effectiveness of TR in the assessment and primary management of neurogenic dysphagia, by exploring the knowledge, attitude and practice of TR personnel in India. These factors were differentiated as those that influence the ecological validity and those influencing effectiveness.

Hence, based on implementation research ideas, the researcher aimed to now implement the new service delivery mode called TR for neurogenic dysphagia assessment and primary management in a resource constrained country such as India, by keeping in mind its effectiveness will be influenced by various factors. Technology related factors such as the

devices and technology used for TR, the current internet speed available in the study location, context related factors such as materials used for the CSE and real-life outpatient clinical settings, clinician related factors such as SLP practising in India, some patient related factors such as severity of dysphagia were incorporated to establish the ecological validity of TR in this phase. A mixed methodology was adopted to meet the aim of this phase, wherein a quantitative method of inter rater reliability was utilized to investigate the effectiveness of TR and a qualitative descriptive analysis to describe the effects of the variables on the effectiveness.

As defined earlier, effectiveness of an ecologically valid TR is its ability to provide desired outcomes, i.e. assess and conduct primary management of neurogenic dysphagia in a real life setting in a resource constrained country. To establish its effectiveness, the outcomes obtained when conducting a neurogenic dysphagia assessment using TR should be similar to that obtained when done the traditional way, i.e. a face to face (FTF) assessment. The FTF assessments were considered as the control to assess the effectiveness of TR. Hence, the inter rater reliability score of percentage exact agreement (PEA) measure and Cohen's Kappa (k) were chosen to investigate this effectiveness. Inter rater reliability needed to be calculated to overcome the degree of subjectivity that may occur based on the researcher's interpretation of the construct. It allows the researcher to identify variables that may be problematic, when there is low PEA (McHugh, 2012). The inter rater reliability is easily calculated and directly interpretable. Its key limitation is that it does not take account of the possibility that raters guessed on scores. It thus, may overestimate the true agreement among raters. However, this issue was overcome with the vast experience in dysphagia of the SLP used in this phase and that most constructs being assessed on the assessment tool were being rated on a 5-level

scale. Hence, the chance of random agreement is reduced (Iacobucci, Grayson & Rust, 2001; Stemler, 2004).

As a rule of thumb suggested by various experts, values from 75-90% of percentage demonstrate an acceptable level of agreement (Stemler, 2004). When there were PEA values of less than 90%, the researcher opted for a descriptive case study method to describe the effect of the patient, clinician or context related factors that could have influenced it. Based on the research stages adapted from that provided by Campbell et. al (2000) and Craig et. al (2008), the researcher considered the use of simulated patient (SP), prior to trialling the use of TR on real patients with neurogenic dysphagia, to rule out any adverse effects during the trial, such as aspiration or choking episode. Simulated patient are persons who are trained and oriented to enact as patients (Barrows, 1968). They should enact the clinical symptoms of the particular patient types. The researcher could make repeated trials with a SP, unlike on real patients, since it can be tiring for them.

This phase was similar to the study done by Sharma (2012), however it was conducted in a resource constrained country in a real life setting of an outpatient clinic. Based on the results from chapter two and four, some factors were included in this phase and some were delimited. Patient factors such as the medical diagnosis and the severity of neurogenic dysphagia were considered. Technology related factors that were included were that Skype® was used as the TR tool for communication between the researcher and the participants, since internet applications like Skype®, Hangout® and face time were mainly used by the TR personnel in India. The SP used a tablet computer whereas the TR-SLP used a notebook computer. The SP had a 3G (third generation wireless mobile telecommunications technology) connection in their tablet computer and the TR-SLP had an 8Mbps wireless

network internet connection speed. Context related factor included a real outpatient clinic setting which was crowded with patients and hence, noisy. Hence the concept of ecological validity was justified to a certain extent in this phase.

As mentioned in chapter one, the research done by Hagge, Nouredine, Brady & Ofstad (2015) showed that SPs could be used for training of speech language pathology and nursing students in the intervention of dysphagia. Hence, based on the results of similar studies, it can be assumed that use of SPs will not adversely influence the ecological validity of the strategy being investigated, considering that the researcher was defining ecological validity as performance of a new intervention mode such as TR in a real life outpatient clinic setting.

A manuscript, reproduced below, will be submitted to the International Journal of Telerehabilitation.

Thus, the manuscript three aimed to investigate if TR can be used effectively for the assessment and primary management of neurogenic dysphagia in India. The objectives for this phase were

- i. To compare the results obtained using CSE through TR mode and face to face mode with the intention to identify if the scores are reliable.
- ii. To examine and explain the effect of the external variables such as internet connection availability and bandwidth, electricity supply, availability of computers and its accessories, audio/visual clarity of TR video/images, knowledge of onsite clinician or the caregiver regarding dysphagia and their skill to assist the TR-SLP,

severity of dysphagia and related comorbidities on the effectiveness of TR in dysphagia assessment.

5.2 Manuscript Three

Investigating the effectiveness of ecologically valid telerehabilitation for neurogenic dysphagia assessment and primary management in a resource constrained country

Abstract

Delivering dysphagia management through telerehabilitation mode has been mostly done under controlled settings in economically advanced countries like USA and Australia. The current study aimed to investigate the effectiveness of TR in the assessment and primary management of neurogenic dysphagia in India. Case study design was employed for the study, wherein quantitative data analysis using PEA and Cohen's Kappa was done to determine the inter rater reliability of scores of the TR-SLP and FTF-SLP on the clinical swallow evaluation proforma and descriptive analysis was conducted to describe the main factors that affect the effectiveness of TR. The results showed high levels of agreement between the offsite TR-SLP and the onsite FTF-SLP on all parameters on the CSE protocol, despite the influence of the various factors that affect its effectiveness. Thus, neurogenic dysphagia can effectively be assessed using remotely located personnel.

Key words: effectiveness, TR, neurogenic dysphagia

Introduction

Telemedicine is widely used in India, considering the large population and other resource constraints such as economic, political and geographical issues with studies having reported on its use in the fields of radiology, surgery and psychiatry (Ayyagari, et. al, 2004; Mohan, et. al, 2012; Dadlani, et. al, 2014). The Apollo group of hospitals has pioneered its use in a project at a secondary level facility in a village called Aragonda, in Andhra Pradesh district in India. Starting from simple web cameras and ISDN telephone lines, the village hospital has a state-of-the-art videoconferencing system and a Very Small Aperture Terminal (VSAT) satellite installed by the Indian Space Research Organization (ISRO). Coupled with this was the Sriharikota Space Center project, which formed an important launch pad of the Indian Space Research Organization in this field (Ganapathy, 2001). Telemedicine programs are actively supported by the Indian Department of Information Technology, Indian Space Research Organization, NEC Telemedicine program for North Eastern states, Apollo Hospitals, Asia Heart Foundation, State governments and several private organizations (Bedi, 2003).

However, the use of TR is not commonly reported in India, with few institutes or therapy centers using it to provide services, such as physiotherapy and speech therapy. One such pioneering central government funded institute is the All India Institute of Speech and Hearing in Mysore, which mainly provides speech therapy to people with Parkinson's Disease and other communication disorders (Center for Rehabilitation and Education through Distance Mode, 2013), as is being done by a few private centers. Use of TR for dysphagia management was not reported in India or any resource constrained country. Considering the dearth of dysphagia experienced SLP in India (Indian Speech and Hearing Association,

2010), TR seems to be a good option for its intervention. Patient access to dysphagia trained speech language pathologists in India is therefore limited (Suryanarayan & Madhoomita, 2008), with a shortage of staff in underserved areas, a possible solution being to adopt telerehabilitation (TR) to assist with patient management (Zampolini et. al, 2008).

The research done on the feasibility or efficacy of using TR for dysphagia management has only been reported in well-resourced countries (Malandraki, McCullough, He, McWeeny & Perlman, 2011; Sharma, 2012; Ward et. al, 2007 to cite a few). This raised questions regarding its use in a resource constrained country such as India, without making any major modifications, where its effectiveness is challenged, wherein effectiveness is defined as measure the degree of beneficial effect under “real world” clinical settings (Moller, 2011). Hence, studies are usually designed to investigate based on conditions of routine clinical practice and on outcomes essential for clinical decisions. Effectiveness of a new mode of treatment delivery needs to be investigated when it has been identified to be feasible under controlled settings, as that done in the economically developed countries. This can be identified by comparing the results obtained from the treatment provided through the new mode and those from the traditional mode. If the results are highly comparable, then the new mode can be acknowledged as effective.

When adapting TR for dysphagia management in a resource constrained country such as India and in a real life clinical setting, many factors affect its effectiveness and they could be internet connectivity and bandwidth, availability of computer and related devices, knowledge of computer use by patient, caregiver and onsite clinician, dysphagia intervention skills of onsite clinician, cause and severity of dysphagia, and other comorbidities of the patients. Thus, acknowledging these variables, the effectiveness of TR for dysphagia

assessment and primary management should be studied before implementing it, for which the results obtained from the dysphagia assessment done through TR needed to be compared to the scores obtained through a traditional clinical swallow evaluation. The comparison of the scores will help to establish the effectiveness of TR in neurogenic dysphagia assessment and primary management.

The study therefore aimed to investigate the effectiveness of TR for assessment and primary management of dysphagia in India, which was attained by comparing the results obtained by conducting the clinical swallow evaluation through TR mode and face to face mode with the intention to identify if the scores are reliable. An objective was to examine and explain the effect of the external variables such as internet connection availability and bandwidth, electricity supply, availability of computers and its accessories, audio/visual clarity of TR video/images, knowledge of onsite clinician or the caregiver regarding dysphagia and their skill to assist the TR-SLP, severity of dysphagia and related comorbidities on the effectiveness of TR in dysphagia assessment that may affect the effectiveness of TR.

Method

Mixed methodological design was used for the study, as the study included both quantitative and qualitative methods, in relation to the objectives of the study. This methodology helped in augmenting and validating the results obtained from one method with that of the other (Creswell & Plano Clark, 2011). Direct observation method was used to conduct the clinical swallow evaluation (CSE) through TR and a descriptive case study method to describe in detail the factors that may have influenced the scores of the CSE.

Ethics approval was obtained for this study from the University of KwaZulu-Natal Biomedical Ethics Research Committee (BREC) with the reference number BFC452/15 (Appendix 1) and from NIMHANS ethics committee, in India with the reference number NIMH/DO/Ethics Sub-committee/30//2016 (Appendix 2).

Participants

Four personnel were involved in the assessment, the telerehabilitation-SLP (TR-SLP) was being based in Abu Dhabi (United Arab Emirates), while the face-to-face SLP (FTF-SLP) was in India with the simulated patient (SP) and an assistant in an outpatient clinic set up for the study. The FTF-SLP had twenty plus years of experience in the intervention of dysphagia. Hence her vast experience and knowledge was relied on for the CSE, which included dysphagia assessment, dysphagia outcome severity rating, diet recommendation and further recommendation to ensure that understanding of each range of severity was similar to the TR-SLP's. She has worked in acute inpatient and outpatient rehabilitation set ups. Three clinicians with over five years of experience in managing patients with dysphagia were identified through purposive sampling. They have been working in an outpatient rehabilitation set up. They portrayed SPs with specific oromotor and swallowing problems. SLP with no experience in dysphagia management were excluded from the study. Informed consent was obtained from the SP (Appendix 6) and the FTF-SLP (Appendix 7).

The main participants of the study were simulated patients (SP) with dysphagia and they were used to eliminate the risk of having undetected aspiration occur in a real patient during the trials. A simulated patient is a patient scenario that is acted out by a healthy individual in such a way as to realistically represent a real patient with specific symptoms or

problems (Battles, Wilkinson, & Lee, 2004). Considering that TR for dysphagia management is a novel method in India, which is a resource constrained country and various external factors like poor internet connection, electricity failures, poor quality of the computer and the related accessories, use of real patients may be risky, if they happen to choke or aspirate during the procedure. Previous studies such were done under controlled settings, wherein the external variables mentioned above could be controlled and the consequences such as choking or aspiration could be intervened by an onsite SLP. Thus, based on the Campbell et. al (2000) model for the sequential stages of research, the researcher has used SP for the current study.

Data collection

The researcher, who led the CSE, was the TR-SLP in Abu Dhabi with Skype® being used as the TR mode. The FTF-SLP was present in a (real) outpatient setting with the SP in India, and did the CSE independently to establish the concurrent feasibility of the TR assessment compared to the standard clinical assessment environment. The TR-SLP in Abu Dhabi used a laptop computer and the FTF-SLP in India used a tablet computer on which Skype was loaded for the assessments. The FTF-SLP had freedom of movement that allowed close up views and the ability to touch the patient to assess oromotor muscle strength but was required to complete the CSE. The assistant's role was to position the patient directly in front of the portable computer system. Each SP was asked to portray one case scenario, except for one SP who portrayed two scenarios. A total of four scenarios were portrayed: one normal SP, one SP with mild dysphagia, one SP with mild-moderate dysphagia and one SP with severe dysphagia. Prior to each assessment, a two hour training course was delivered which was designed to help the SPs play their roles and were informed about the method and

scenarios. They were given details of the diagnosis, general medical state, oromotor function, aspiration risk of certain food and fluid consistencies, and overall dysphagia severity. An external SLP was used to conduct the training for the SP to avoid bias, who were trained in all four scenarios. Further instructions and advice were given based on the simulated patients' performance before they were assessed by the TR-SLP and FTF-SLP. The case details were provided only to the SP and no information other than age, sex and a brief medical history was provided to the assessing TR-SLP and FTF-SLP. While the one SP was being assessed, another SP served as the assistant in the room to provide technical support to enable the TR-SLP to conduct the assessment.

The FTF-SP who was in the room with the patient and completed the clinical swallow examination (CSE) proforma independent of the TR-SLP. The food and fluid consistencies used in the CSE were consistent with the diet framework provided by the International Dysphagia Diet Standardization Initiative (IDDSI). During the assessment, the assistant aided the TR-SLP with the oro-motor and food and fluid trials, and repositioned the computer tablet camera. Diagnostic and management decisions were not verbalized between the FTF-SLP and TR-SLP, during the assessment, so as not to confound their respective decisions.

Results

The effectiveness of TR for the assessment and primary management of neurogenic dysphagia was done by calculating the percentage exact agreement (PEA) and Cohen's Kappa scores between the scores of the TR-SLP and FTF-SLP on the major categories of the CSE, which were oral motor assessment, tongue function, fluid assessment, food assessment, severity rating and diet recommendation, for the quantitative analysis. The results were also

presented as a qualitative case study with each case being reviewed under the main categories of internet connection availability and bandwidth, electricity supply, availability of computers and their accessories, audio/visual clarity of TR video/images, knowledge of onsite clinician or the caregiver regarding dysphagia and their skill to assist the TR-SLP, severity of dysphagia and related comorbidities, and possible reason behind the different scores obtained on the CSE. Overall, all cases showed 100% PEA for general alertness, comprehension and oral hygiene on the CSE proforma.

In the current study, similar to previous research (Hill et al., 2009b; Sharma et al., 2011; Theodoros et al, 2008; Waite et al., 2010; Ward et al., 2009; Ward et al., 2007), a level of 80% or higher PEA was used as clinically acceptable levels of reliability. In addition, Cohen's Kappa values were calculated and interpreted using the level of agreement criteria set by Landis, and Koch (1977) (0.0 - 0.2: slight; 0.2 - 0.4: fair; 0.4 - 0.6: moderate; 0.6 - 0.8: substantial; 0.8 - 1.0: almost perfect). In the current study, a level of 0.6 or higher (moderate to perfect agreement) was set as the accepted criterion, considering that there can be various factors that influence the effectiveness of TR in a resource constrained country.

Case A- mild dysphagia

The medical diagnosis of this simulated patient was acute ischemic CVA. The diagnosis made by the TR-SLP and FTF- SLP was level 5 on Dysphagia Outcome and Severity Scale (DOSS), which is mild dysphagia, the PEA being presented Table 1. Oral motor assessment included assessment of dentition, oral hygiene, jaw, lips, cheek, pharyngeal and laryngeal functions with a high inter rater reliability score (93.75%) being reported. Assessment of tongue functions provided 100% inter rater reliability. All decisions on food texture decisions showed 100% inter rater reliability on soft food but 77.78% on regular diet.

The factors that could have led to the low scores are discussed in detail below, with the severity rating indicating a 100% inter rater reliability. All parameters except the assessment of regular food was within the set criterion of Kappa.

Table 5.1: Percentage exact agreement and kappa scores for case A

Parameters assessed	PEA	Kappa
1. Oral motor assessment	93.75%	0.855
2. Tongue function	100%	1.0
3. Fluids		
a. Mildly thick fluids	88.89%	0.667
b. Slightly thick fluids	88.89%	0.667
c. Thin fluids (Cup)	100%	1.0
d. Thin (sips)	100%	1.0
4. Food		
a. Soft food	100%	1.0
b. Regular food	77.78%	0.22
5. Diet recommendation	100%	1.0

6. Severity rating	100%	1.0
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Case B- mild to moderate dysphagia

The medical diagnosis of this SP was traumatic brain injury. Patient was seen to have receptive and expressive language issues, such as being able to follow only simple commands with 2-3 repetitions. She may also have diminished cognitive abilities which were not assessed during this study. Both SLPs diagnosed her with level 4 dysphagia, which is mild to moderate dysphagia, the PEA being presented in Table 2. The inter rater reliability scores for oral motor assessment and fluid assessment were 100% while tongue function was 90%. Solid assessment produced 88.89% on minced food and 77.78% on soft food. These low scores may be influenced by the various external factors. Diet recommendation and severity rating showed 100% reliability. Kappa values were within the set criterion for all the parameters in this case.

Table 5.2: Percentage exact agreement and kappa scores for case B

Parameter assessed	PEA	Kappa
1. Oral motor assessment	100%	1.0
2. Tongue function	90%	0.88
3. Fluids assessment		
a. Moderately thick fluids	100%	1.0

b. Mildly thick fluids	100%	1.0
c. Slightly thick fluids	100%	1.0
d. Thin fluids (Cup)	100%	1.0
e. Thin (sips)	100%	1.0
4. Food assessment		
a. Soft food	77.78%	0.63
b. Minced food	88.89%	0.73
5. Diet recommendation	100%	1.0
6. Severity rating	100%	1.0

Case C- severe dysphagia

The medical diagnosis of this SP was an old cerebro vascular accident, with the diagnosis made by both the SLPs being level 1 on DOSS, which is severe dysphagia. The patient also presented with dysarthria, hoarse voice (which may be due to vocal fold paralysis, although not diagnosed) and reduced receptive language skills (patient was able to follow simple commands with repetition). As the severity of dysphagia increased, the inter

rater reliability decreased on most parameters, with oral motor assessment having the lowest score of 68.75%. This could be associated with factors such as audio and visual clarity, which may have been affected by the internet connection, its bandwidth, visual and audio quality. However, there was 100% inter rater reliability on tongue functions, as these are more overt movements when compared to those of the oral motor examination. Nevertheless, fluids and food texture assessment showed higher inter rater reliability, while diet recommendation and severity rating, continued to have 100% reliability, which is comparable to the other cases.

The kappa value for oral motor assessment (0.22) had only fair level of agreement. However, all other parameters had high levels of reliability, with 4 parameters (fluid assessment of extremely thick with $k=0.615$ and moderately thick with $k=0.725$, food assessment of minced food with $k=0.74$ and pureed food with $k=0.712$) tending towards the lower side. This may be attributed to the severity of the case.

Table 5.3: Percentage exact agreement and kappa scores for case C

Parameter assessed	PEA	Kappa
1. Oral motor assessment	68.75%	0.22
2. Tongue function	100%	1.0
3. Fluids assessment		
a. Extremely thick fluids	88.89%	0.615
b. Moderately thick fluids	88.89%	0.725
c. Thin fluids	100%	1.0
4. Food assessment		

a. Soft food	100%	1.0
b. Minced food	88.89%	0.74
c. Pureed food	88.89%	0.712
5. Diet recommendation	100%	1.0
6. Severity rating	100%	1.0

Case D- Normal

The final SP was a normal case, with a SP who complained of occasional coughing when drinking water and was medically diagnosed with bronchitis. Both SLPs made a diagnosis of level 7 on DOSS, which is normal. There was 100% inter rater reliability since the case was normal and there was no ambiguity in the decision making. The kappa values were all perfect with 1.0.

Table 5.4: Percentage exact agreement and kappa scores for case D

Parameter assessed	PEA	Kappa
1. Oral motor assessment	100%	1.0
2. Tongue function	100%	1.0
3. Fluid assessment		

a. Thin fluids	100%	1.0
4. Food assessment		
a. Regular food	100%	1.0
5. Diet recommendation	100%	1.0
6. Severity rating	100%	1.0

All four simulated cases resulted in high inter rater reliability in all the 6 parameters, except for case C, who was diagnosed with severe dysphagia. The Cohen's kappa values were also within the acceptable set criterion except for case C having 4 parameters (fluid assessment of extremely thick with $k= 0.615$ and moderately thick with $k= 0.725$, food assessment of minced food with $k=0.74$ and pureed food with $k= 0.712$) tending towards the lower side. This may be attributed to the severity of the case.

Hence, it was identified that the greater the severity of dysphagia, the lower the inter rater reliability. This suggests that the patient's comorbidities such as reduced receptive and expressive language and speech skills (dysarthria, apraxia or a dysphonia due to vocal fold paralysis) can affect the TR results, also identified in the study by Ward et. al (2012). This difference in scoring of the oral motor evaluation and tongue functions could be associated with the external variables, such a poor internet connection, thus affecting the audio and visual quality of the TR video. The study was conducted in an outpatient clinic setting, where a pulse oximeter is generally unavailable.

Discussion

Previous studies of TR in the intervention of dysphagia has been discussed specifically in economically developed countries such as the United States of America and Australia (Sharma, et. al, 2011; Ward, et. al, 2012; Malandraki, et. al, 2013; Ward, et. al, 2014; Burns, et. al, 2016). Thus, it was uncertain if TR could be implemented in a resource constrained country such as India and in a real life setting, making it necessary to evaluate the effectiveness of a TR. The present study therefore wanted to establish if TR can be used in a daily clinical setting for the assessment and primary management of neurogenic dysphagia, in India, where many factors could influence the its effectiveness.

It identified that TR is effective in dysphagia assessment and primary management in India due to the high inter rater reliability between the scores obtained on the clinical swallow evaluation protocol by the TR-SLP and FTF-SLP, using the 6 end points- oral motor evaluation, tongue function, fluid assessment, food assessment, severity rating, diet recommendations, except in case C. This could be associated with the severity of the dysphagia. Nevertheless, there was an indication that TR results were comparable to that of a traditional setting, i. e. a face to face clinical swallow evaluation. However, TR was not effective in identifying silent aspiration and pulse oximetry readings may not be a solution for this, as a number studies have concluded that pulse oximetry is not sensitive to identify silent aspiration (Ramsey et. al, 2006; Leder, 2000), which suggests that, TR may not be effective in identifying this condition.

Severity of dysphagia and related comorbidities (patient related factor)

The results obtained showed that greater the severity of the neurogenic dysphagia, the lower the scores obtained on the CSE, as seen in case C and D. The related comorbidities, such as slurred speech, hoarse voice and diminished receptive language skills of the patient, may also have influenced the scores. Thus, all these factors will have an influence on the effectiveness of TR in managing neurogenic dysphagia in a resource constrained country, such as India.

Internet connection availability, its bandwidth and electricity supply (technology related factors)

As many rural areas of India are limited by the availability of high speed internet connection, it is important to ensure system functionality can be fully achieved at low bandwidths (Gnanasambandam et. al, 2012). However, it is acknowledged that in instances where internet connectivity has greater speed, the clarity of the audio and video would be enhanced. A store-and-forward application may be beneficial for clinical decision making in cases of low bandwidth internet, as with those used by Ward et. al (2012) and Sharma et. al (2011).

Availability of computers, its accessories and audio/visual clarity of TR video/images (technology related factors)

During the study, the lack of availability of a suitable device such as a desktop personal computer or a laptop was noted as possibly affecting the TR service. A tablet computer was used on the patient's site during this study, which affected the visual range, with the assistant positioning the camera appropriately whenever required. The quality of the

inbuilt camera of the device and its functioning such as the ability to zoom in for the TR-SLP to have a clearer view of the oral structures may have influenced the scores of the CSE. This in turn influenced the effectiveness of TR, and hence, being similar for the effect of the quality of the inbuilt microphone and speakers.

Outpatient clinic setting (context related factors)

The study setting was a real outpatient speech therapy clinic. Hence, the noise of the crowd in the clinic and the inappropriate seating of SPs influenced the audio-visual clarity of the video, with the SP not being able to comprehend the commands appropriately. This had an impact on the effectiveness of TR

Thus, variables such as internet connection availability and bandwidth, electricity supply, availability of computers and their accessories, audio/visual clarity of TR video/images, knowledge of onsite clinician or caregiver regarding dysphagia and their ability to assist the TR-SLP, and severity of dysphagia and related comorbidities can have an important impact on the results obtained using TR and their effects being larger in resource constrained country due to the various political, social and geographical factors.

The results obtained in this study were in line with the findings of previous studies from the economically developed countries that identified that TR was feasible for the assessment or management of dysphagia, i.e. TR can be used easily for dysphagia assessment and/or management. Further, from this study, TR has been identified as effective in neurogenic dysphagia assessment and primary management, which is a boost for the intervention of dysphagia in India considering the dearth of dysphagia experienced SLP in

the country. The results showed the TR is effective, i.e. it is successful in producing desired outcome in dysphagia assessment.

The use of mixed methodology added more value to the results obtained, since it increased the comprehensiveness of overall findings, by showing how the qualitative description provided explanations for statistical data (quantitative) and it expanded the dimensions of the research topic, since the descriptive case study method was able to explain how the various factors could have influenced the results obtained during the CSE through TR. A study done by Sharma et. al (2012) have also discussed that dysphagia assessment done through TR could not identify silent aspiration.

The findings of this study are an added asset to the field of TR as well as, bridge the gap in knowledge regarding its use in a resource constrained country, which has not been probed into in the past. The factors identified could be generalised to all resource constrained country, since economic, political and geographical issues may be similar. Thus, a SLP who is considering using TR for the intervention of dysphagia in such a setting must keep these factors in mind when analysing the results obtained it.

The main limitation of the study can be pointed towards the use of only SPs rather than real patients with neurogenic dysphagia. However, the TR-SLP and FTF-SLP were unaware regarding the severity of neurogenic dysphagia portrayed by the SP and still there was high inter rater reliability between the raters. Similarly, due the small sample size of four SP, the findings cannot be generalised to broader clinical settings. However, there is no denial that the results provide valuable preliminary information for future research of TR in resource constrained country.

Conclusion

The current study investigated the effectiveness of a TR system for the assessment and primary management of neurogenic dysphagia in a resource constrained country. The results showed high levels of agreement between the offsite TR-SLP and the on-site FTF-SLP on all parameters on the CSE protocol, despite the influence of various external factors that affect the effectiveness of the system. Thus, neurogenic dysphagia can effectively be assessed using remotely located personnel. Research is now needed to extend this evidence and increase the generalizability of the results by performing trials of the system with a large cohort of patients, and across all types of dysphagia etiology and severity, and to explore patient and clinician satisfaction in using TR. Although the current findings are still preliminary, the data contributes to the growing evidence base supporting the delivery of speech language pathology services via TR in resource constrained country.

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5.3 Summary of the chapter

Based on the literature review conducted in chapter two, it was identified that previous studies using TR for the intervention of dysphagia was mainly conducted in economically developed countries and under controlled settings. Hence, the question regarding the ecological validity and effectiveness of TR was raised by the researcher, which led the shift in paradigm from a positivist to a constructivist one, which was new in the field of TR for the intervention of dysphagia. This brought the researcher to consider the use of TR for neurogenic dysphagia assessment and primary management in a real life outpatient clinic setting in a resource constrained country, to investigate if desired outcomes will be obtained.

The various factors that affect ecological validity that were identified in phase one and two, which are patient, clinician, technology and context related factors needed to be acknowledged when conducting such an investigation. The study privileged certain variables and delimited the others, since it could not accommodate all the variables identified under one study. By including patient related factors, technology related factors and context related factors such as conditions of a real life clinic setting, the ecological validity of TR was established to a certain extent. Although simulated patients were used (based on the continuum of clinical evidence as provided by Campbell et. al in 2000 and Craig et. al in 2008) for the study, the TR-SLP and FTF-SLP were unaware regarding the severity of neurogenic dysphagia of the SPs.

To investigate the effectiveness of TR, inter rater reliability scoring using percentage exact agreement and Cohen's Kappa were used, between the scores obtained on CSE by the TR-SLP and FTF-SLP. The quantitative data analysis using PEA and Cohen's Kappa showed

that TR was effective in conducting neurogenic dysphagia assessment and primary management since there were high inter rater reliability in all the cases studied. A descriptive analysis of the results obtained could explain the reason for the variation in scores on certain parameters of the CSE in each case, in relation to the factors affecting the ecological validity. This qualitative descriptive analysis could explain how the various factors could have influenced the performance of the patient and clinician.

Thus, in comparison to the previous studies that have conducted the intervention of dysphagia using TR in controlled settings in economically advanced countries, there were slight variations in the inter rater reliability, which can be attributed to the factors influencing the ecological validity and hence, the effectiveness. These factors cannot be excluded in a real life clinical setting when using TR every day. Although, there may be variations in the scores on a CSE, TR is still effective in the assessment and primary management of neurogenic dysphagia, in a country where there is a dearth of dysphagia experienced SLP. The results obtained are clinically significant and TR can be a hopeful solution.

Chapter Six

Synthesis and Critique

6.1 Introduction

The overall study aimed at understanding if an ecologically valid TR system can be used effectively to assess and do primary management of neurogenic dysphagia in a resource constrained country such as India. This was conducted on recognizing the increasing population disorders like cerebrovascular accident, with neurogenic dysphagia as a symptom, in India due to the changing modern lifestyle (Das et. al, 2007) which has led to an increased demand in their intervention. This requires an initial bedside swallow assessment and primary management, by a SLP, which includes recommendation for further management as per the standards set by the American Speech and Hearing Association (ASHA). However, owing to a dearth of dysphagia experienced SLP and less access to them due to geographical, economic and political reasons in resource constrained countries, appropriate management may not be happening. Thus, TR seems to be a good solution to this, thereby improving the access to dysphagia services and consequently receiving the appropriate intervention. The patients with neurogenic dysphagia in an underserved area in a resource constrained country, such as India could access a dysphagia experienced SLP in another city within the country or outside, using TR.

6.2 Summary of findings of the phases

The researcher identified a need for exploring the available literature on the use of TR for the intervention of dysphagia. The narrative literature review (Oxman, Cook & Guyatt,

1994; Green, Johnson & Adams, 2006) aided to understand that TR for dysphagia management is still in its infant stages and that TR was a feasible method for the intervention of dysphagia. However, there is a gap in knowledge regarding its use in resource constrained countries, since all studies were conducted in economically developed countries such as Australia and USA, such as those done by Ward et. al (2007), Sharma, Ward, Burns, Theodoros and Russel (2011), Malandraki, McCullough, He, McWeeny and Perlman (2011), and Ward, Sharma, Burns, Theodoros and Russell (2012), to cite a few. Moreover, the studies were conducted under controlled settings, such as Sharma, Ward, Burns, Theodoros and Russel (2011), Ward, Sharma, Burns, Theodoros and Russell (2012), Ward, Burns, Theodoros and Russell, (2013), and Burns, Wards, Hill, Phillips and Porter (2016) when the TR-SLP and patient were in separate rooms within the same building or department. The benefits and limitations reported by each study helped to identify the possible factors that can influence the ecological validity of TR, i.e. when TR is conducted in a real life clinic setting, which were internet connectivity and bandwidth, audio-visual inaccuracy, effects of medical comorbidities of patients such as hearing or cognitive impairment, etc.

Thus, the ecological validity of this new intervention method and its effectiveness was doubtful. The literature review thus, identified the main concepts of the study to be ecological validity and effectiveness of TR. When adopting it into a resource constrained country, its ecological validity and the variables affecting its effectiveness cannot be ignored. The researcher's perspective thus shifted from positivism to constructivism which aided to explain how people know what they know (Warmelink, et al, 2015). The researcher recognized the value of practical utility of existing theories, conclusions and subjective influences of the patients and SLP during the TR intervention (Lyons, Bike, Ojeda, Johnson, Rosales & Flores, 2013). Ontologically, reality, i. e. ecological validity and effectiveness of

TR, is composed by context related factors. Epistemologically, reality needed to be interpreted to identify the underlying meaning of the factors influencing the ecological validity and effectiveness of TR (Guba & Lincoln, 1982), which formulated the theoretical and methodological perspective of the further phases of the study (Scotland, 2012).

As mentioned earlier, the previous studies identified have been more of a positivist focus, by obtaining results under controlled settings in economically developed countries and was concerned with gaining knowledge in a world which is objective using scientific methods of enquiry. However, when considering ecological validity of TR, there are various factors that can influence it, since it involves human interaction in real life settings, which in turn can affect its effectiveness. These factors that may influence the outcome of a TR service delivery can be technology related factors, patient factors, clinician factors and context related factors. Considering the influence of these factors, the effectiveness of the ecologically valid TR in neurogenic dysphagia management was investigated, wherein effectiveness in this context refers to its performance for neurogenic dysphagia assessment in a real life setting, considering that India is a resource constrained country.

The main research question for the overall study was if an ecologically valid TR can be used effectively to assess and conduct primary management of neurogenic dysphagia in a resource constrained country. To answer this big question, the researcher identified the need to follow an interrogative model of inquiry. By following this model, there was a need to answer smaller questions to fulfill the main aim of the study. Thus, the researcher determined the need to initially explore the use of TR in a resource constrained country, which helped to identify the factors that influence the ecological validity and effectiveness of TR. This led to phase two of the study.

The researcher aimed to identify the factors affecting ecological validity of TR in India by exploring the knowledge, attitude and practice (Kaliyaperumal, 2004; Launiala & Kulmala, 2006; Peltó & Peltó, 1997; Richards et. al, 2005; World Health Organization, 2008; Yoder, 1997) of TR personnel by conducting in depth semi structured interviews following an exploratory research design, which helps to explore ideas and insights into a new field and usually deliver new information about the topic for research (Creswell & Plano Clark, 2011); wherein the questions were developed based on the results from the literature review. the researcher relied on the participants' views or interpretation of the situation (Warmelink et al 2015). The methodology chosen was based on the constructivist paradigm, only when a detailed answer for the research problem could be achieved.

The knowledge of the professionals regarding TR aided in understanding its current status in India, which revealed that it has been in use in India mainly in the medical fields like radiology, surgery and psychiatry. Not many rehabilitation professionals were using TR and it has not been used for dysphagia management. The participants equally voiced the lack of central or state government rules and regulations that govern the practice of TR in India. The attitude of the participants revealed that TR was equally acceptable by professionals and patients, which is positive to the growth of TR in India. Practice disclosed that TR was done through the various instant messaging applications like Skype®, Hangout® or using face time on iPhone. There was no specific 'TR device' that was developed for rehabilitation service delivery.

The results provided a more detailed conceptualization of the various factors that affect the ecological validity of TR services in India. The main issue faced is the power

failure, which happens at least once in urban and rural areas of India, which could lead to internet disconnection, which could disrupt TR service delivery. Lack of computer literacy of patients, caregivers and on site clinician can be detrimental to TR service delivery. Similar would be the case when there are no computers and accessories available or old ones are being used, which can happen even in urban cities, since they are expensive. This can hinder the audio-visual clarity at both ends, thus not providing accurate input and output for tele-mode services. Another factor was the severity of the disorder and the associated comorbidities that were being assessed or intervention being provided. This can influence the ecological validity, which was emphasized mainly by the SLP professionals.

As the severity of the disorder increased, therapy through TR mode proved to be more challenging than a face to face session, since occasionally tactile input during the assessment or therapy is deemed highly inevitable. Sessions need to be made creative for any paediatric cases to keep their interest going during the sessions, which can be difficult using TR where the therapist cannot physically engage with the patient. The lack of government infrastructural support appears to be the main element influencing all the other factors that influences the ecological validity of a new intervention system such as TR. The major constraints in infrastructure could be the political and regulatory risk such as formulating central government level rules and regulations to govern TR services, which would lead to its streamlining and obstacles to access financing or funding.

The main concepts identified from this phase were resource constrained country and real life setting that are related to ecological validity and effectiveness respectively. The researcher identified that there are individual level, health service delivery level, health sector level, social level, political and economy level constraints influence the ecological validity of

a new intervention mode such as TR when imported to a resource constrained country. Its effectiveness is influenced by patient factors and context related factors, as explained in chapter four. All these factors are a result of a lack of infrastructural support by the government. However, the current Prime Minister of India has launched the ‘Digital India’ campaign, which can be highly beneficial for the growth of TR services in India. This campaign could put in place appropriate rules and regulations to govern TR practice including for rehabilitation services and hence, streamline the infrastructure for its advancement.

This thick description of data in this phase, led to the next phase of formulating the use of TR for the assessment and primary management of neurogenic dysphagia in India. The factors influencing the ecological validity and hence, the effectiveness of TR needed to be addressed when implementing it in India. It also suggested that strategies to overcome them must be directed at creating and supporting opportunities in resource constrained country to meet patients’ needs, irrespective of location. Patient related, technology related and context related factors (as explained in chapter five) were incorporated in the study to establish ecological validity of TR. Effectiveness can be measured in multiple ways in medicine: patient satisfaction, patient quality of life, concordance of diagnosis, management reliability/accuracy, and patient outcome (Maiberger, 2015). However, the researcher chose to use the inter rater reliability of assessment and primary management using the clinical swallow evaluation. Most of the factors identified in phase two were incorporated in this phase, which were patient related, technology related and context related one including conducting the investigation in a real life outpatient clinic setting. The researcher identified that the technology and context related factors defined ecological validity. This is based on Schmuckler (2001) who stated that the ecological validity of a setting is its representativeness

and naturalness, with a primary consideration that the environment contains crucial features of naturalistic settings. However, SPs were used and the justification for the same was explained in chapters one, three and five.

Theoretically and methodologically, a mixed methodological design using direct observation method was utilized for this phase. The effectiveness of TR was analysed by comparing the results obtained by conducting a clinical swallow evaluation of simulated patients by a face to face SLP (the traditional clinical swallow assessment method) who was on site with the SP and through Skype® by a TR-SLP, who was in Abu Dhabi. The results showed that TR is an effective method for the assessment of neurogenic dysphagia in a resource constrained country such as India. This is because, there was high percentage exact agreement and Kappa values (inter rater reliability) between the scores, despite the effect of various factors that could affect it. The study identified that the greater severity of dysphagia and comorbidities, the lesser the effectiveness, since lower percentage exact agreement score was seen in one case, who was diagnosed as severe neurogenic dysphagia. During this phase, it was seen that an assistant can play an important role during TR service delivery, whose computer literacy and ability to follow instructions provided by the TR-SLP is vital. This could be a possible suggestion for the future of the service delivery through tele-mode, wherein an assistant could receive prior training to follow the instructions of the TR-SLP.

Availability of good quality computers and accessories are also important since this influences the audio-visual clarity of TR. Although, there were no power failures during the data collection, it can be identified that such an incident during a dysphagia assessment using TR can be detrimental to the process and the patient, because the TR-SLP could miss out on a crucial sign of dysphagia or the whole assessment may need to be discontinued if the power

failure lasts for long durations. This could have a major influence on the effectiveness of TR for the intervention of dysphagia in a resource constrained country. Nevertheless, TR is a recommendable effective solution for neurogenic dysphagia assessment in India.

Overall, the study identifies the need to shift from a positivist to constructivist focus when considering importing a new service delivery system like TR from an economically developed country to a resource constrained country or even from a controlled setting to a real life clinical setting. It was identified that not just TR, but there are various other technology, human and contextual factors that can influence the ecological validity. The researcher could learn and explore through experience, as explained by the constructivist paradigm (Bhattacharjee, 2015).

The use of various data sets through narrative literature review, in depth semi structured interviews and direct observation of CSE using TR, to identify answers for smaller questions to meet the bigger aim of the overall study, aided in accentuating the clinical relevance of the findings and its important contribution to the field of TR, specifically for the intervention of dysphagia. The qualitative results obtained first through the narrative literature review and semi structured interviews added more weightage in the study interpretation and in formulating the path for quantitative data collection (Hanson 2005). The quantitative data obtained from the direct observation using the CSE was provided a qualitative analysis perspective to explain the effect of the factors influencing ecological validity on the effectiveness of TR. Thus, the qualitative descriptive analysis provided a more meaningful description of the phenomenon. The constructivist paradigm brought the researcher closer to the participants through the intense interactions using in depth semi structured interviews and direct observation (Ponterotto, Mathew & Raughley. 2013).

6.3 The current study

The current study recognized that when a new intervention tool/mode, that has been shown to be efficient or efficacious when conducted under controlled settings in economically developed countries, is considered to be imported to other countries, its ecological validity and hence, its effectiveness cannot be ignored. When shifting the theoretical and methodological focus from positivist (objectivity) to constructivist (ecological validity), the results obtained from previous studies using TR for the intervention of dysphagia appears to lack generalizability. Its performance may not be in line with that obtained during previous studies. Hence, this study identified these factors and has been illustrated in figure 6.1.

The findings of this study can be applicable to any field, trying to import a new intervention tool/mode to a real-life setting in a resource constrained country. The current study can be generalised to the use of TR for any kind of speech and language intervention and possibly other rehabilitation disciplines. The factors identified could definitely play a role in the effectiveness of TR when providing assessment and/or management services to any kind of disability in a real-life setting in a resource constrained country such as India.

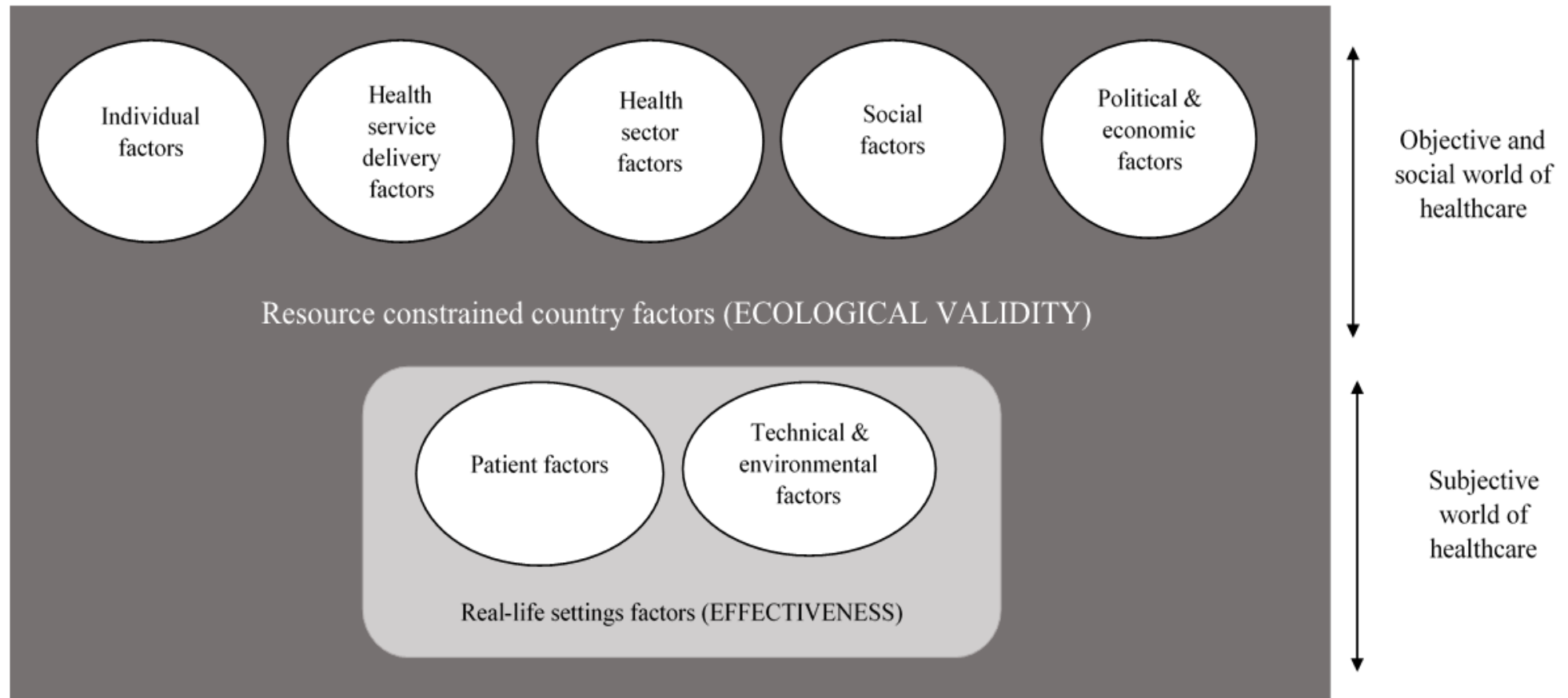


Figure 6.1: Finding of the current study

Hence, the researcher identified that any kind of intervention tool/mode is influenced by multiple factors, which agrees with the concept of ecological validity and effectiveness. The researcher is able to support her findings using the theoretical explanations provided by Mosadeghrad (2014) and Princeton (2015). Mosadeghrad (2014) identified patient related, provider related and context related factors as those affecting the quality of a health care service. The researcher acknowledges that these factors are indeed influencing the effectiveness of the service provided. Princeton (2015) identified objectivity, subjectivity and social perspectives of healthcare that needed to be considered for explaining the quality and hence the effectiveness of a new intervention tool/mode. The researcher identified that the factors explained by Mosadeghrad (2014) fall under the subjectivity factors explained by Princeton. The main concepts identified by the researcher fall under the framework explained by Princeton.

As explained by her, the objective world of healthcare encompasses the professional technical knowledge, obtained through academic training and professional experience, of the healthcare provider or SLP using TR for intervention. It explains the understanding of the patient's diagnosis, severity and intervention methods, in combination with the overall context related factors. The researcher identified this as an important factor (As identified in chapter two and four), wherein the TR-SLP should have a good knowledge regarding the intervention of dysphagia and the use of TR for the same. The current study could bring out the point of the dearth of dysphagia experienced SLP in resource constrained countries. There is also a drawback of TR not being taught as an academic subject, since it is a new mode of intervention.

The subjective world includes patient factors as well as the health care provider (SLP in this study) factors. The patient level factors include their diagnosis, severity of disorder and

awareness regarding the disorder and appropriate treatment. In this study, the researcher could identify that the severity of neurogenic dysphagia and related comorbidities influence the effectiveness of TR in a real-life setting. Moreover, their acceptance of TR as a possible intervention mode and attitude/behaviour on the day of intervention play an important role in the outcome of the intervention. The health care provider or SLP factors include their attitude or behaviour. From chapter four, it was identified that the acceptance of TR other professionals was mixed. In a resource constrained country such as India, where the health care providers are burdened with their own clinical work and hence, back out from performing TR. moreover, their ego and attitude also stop them referring to other health care providers providing TR. However, medical professionals such as doctors have accepted TR for speech language therapy services due to the excessive demand for them.

The social world of health care identifies that the knowledge we gain is through interpretation of the interaction between the patient and the health care provider. The health care service delivery, health sector, social, political and economic factors can be aligned under the social world. The researcher thus, identified that the objective and social world factors are influencing the ecological validity of a new intervention mode/tool when imported to a resource constrained country and the subjective factors can explain its influence on the effectiveness of the intervention mode/tool.

6.4 Limitations and future recommendations

The main limitation of the study can be pointed towards the use of only SPs rather than real patients with neurogenic dysphagia. However, the researcher can contend for this since the whole study followed the concept borrowed and adapted from the continuum of clinical evidence

models by Campbell et. al (2000) and Craig et. al (2008) as explained in the chapter one and three. However, the TR-SLP and FTF-SLP were unaware regarding the severity of neurogenic dysphagia portrayed by the SP and still there was high inter rater reliability between the raters. Similarly, due the small sample size of four SP in study two, the findings cannot be generalised to broader clinical settings. However, there is no denial that the results provide valuable preliminary information for future research of TR in resource constrained country.

While it was beyond the scope of the present study to address the use of TR for dysphagia assessment on real patients and management in terms of dysphagia therapy, the results are useful for dysphagia experienced SLP in India as this is a novel information, which can help in their practice, considering the dearth of dysphagia experienced SLP in India. Thus, patients from remote areas or underserved areas in India can connect with a dysphagia experienced SLP who may be in a metropolitan city within or outside India. This can also solve the issue of organizations wanting to recruit dysphagia experienced SLP, to a certain extent.

The results obtained from the current study feed motivation for future studies using real patients, first to be done in a controlled setting to reduce the risk of the consequences due to aspiration or choking during the assessment. Care must be taken to ensure an uneventful session. The results are an added asset to the knowledge bank in the field of TR in speech language pathology (for dysphagia management and to a certain extent for SLP intervention in other disorders) since not many studies have been conducted in resource constrained country or low income countries like India. The issue related to disruption in dysphagia assessment using TR due to power failures or poor internet connection, can be alleviated with the use of a store-and-forward method, where patient information and digital images are captured, packaged as a case

file, and transferred via telecommunication services to a dysphagia experienced SLP who then responds with a diagnosis and therapeutic recommendations, which is also known as asynchronous telecommunication. However, this may call for additional time and the presence of an onsite clinician who can do the assessment appropriately. Future research can also consider developing a new TR device with the help of Information Technology (I.T.) personnel.

The results of the current study will help and be an inspiration in future large scale studies in resource constrained country and is food for thought for those already using TR for speech language therapy services in such settings.

6.5 Conclusion

The study identified that TR is a feasible and effective method for neurogenic dysphagia assessment and primary management in a resource constrained country, even while considering the various factors that can influence it. This series of studies as part of the overall study has identified the scope of TR for the intervention of dysphagia in India, along with identifying the differences in how the tele-mode services work in the economically developed countries and the resource constrained countries such as India. The importance of understanding and incorporating these differences and hence, the factors that may affect the ecological validity and thus the effectiveness of TR has been highlighted. TR can be an effective mode of service delivery that can be provided to patient with neurogenic dysphagia who are unable to access or attend the conventional intervention of dysphagia. The results obtained from this study can be generalised for the use of TR with any kind of speech language therapy in resource constrained country. The future of TR for the intervention of dysphagia and possibly other speech and language disorder

in India is positive considering the rapid growth of technology in the world and with the favourable support from the current central government in India, which is advocating for 'Digital India'. A fair vision regarding the future of the health care needs in India will be valuable for the growth and success of TR particularly for rehabilitation services in India.

The findings of the overall study identified the need for treating a new intervention as unique, developing in relation to a complex and potentially unique set of ecological conditions. The researcher identified the need for using a contextually guided framework when developing interventions such as TR, which in turn can improve its effectiveness.

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8. Appendices

1. Biomedical Research Ethics Committee Approval for the study



20 September 2016

Mrs Ayanikalath Narayanan Sona
Speech Language Pathology
College of Health Sciences
sonanarayanan4@gmail.com

Dear Mrs Sona

Protocol: Developing and evaluating the effectiveness of an ecologically valid tele rehabilitation system for assessment and primary management of adult neurogenic dysphagia in India.

Degree: PhD

BREC reference number: BFC452/15

The Biomedical Research Ethics Committee (BREC) has considered the abovementioned application at a meeting held on 08 December 2015.

The study was provisionally approved by BREC pending appropriate responses to queries raised. Your responses dated 19 January 2016 and 13 August 2016 to queries raised on 23 December 2015 and 19 February 2016 have been noted and approved by the Biomedical Research Committee at a meeting held on 13 September 2016. The conditions have now been met and the study is given full ethics approval and may begin as from 20 September 2016.

This approval is valid for one year from 20 September 2016. To ensure uninterrupted approval of this study beyond the approval expiry date, an application for recertification must be submitted to BREC on the appropriate BREC form 2-3 months before the expiry date.

Any amendments to this study, unless urgently required to ensure safety of participants, must be approved by BREC prior to implementation.

Your acceptance of this approval denotes your compliance with South African National Research Ethics Guidelines (2015), South African National Good Clinical Practice Guidelines (2006) (if applicable) and with UKZN BREC ethics requirements as contained in the UKZN BREC Terms of Reference and Standard Operating Procedures, all available at <http://research.ukzn.ac.za/Research-Ethics/Biomedical-Research-Ethics.aspx>

Pg. 2/...

Biomedical Research Ethics Committee

Professor J Tsoka-Gwegweni (Chair)

Westville Campus, Govan Mbeki Building

Postal Address: Private Bag X54001, Durban 4000

Telephone: +27 (0) 31 260 2486 Facsimile: +27 (0) 31 260 4609 Email: brec@ukzn.ac.za

Website: <http://research.ukzn.ac.za/Research-Ethics/Biomedical-Research-Ethics.aspx>

1910 - 2010
100 YEARS OF ACADEMIC EXCELLENCE

Edgewood Howard College Medical School Pietermaritzburg Westville



20 September 2016

Mrs Ayanikalath Narayanan Sona
Speech Language Pathology
College of Health Sciences
sonanarayanan4@gmail.com

Dear Mrs Sona

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Degree: PhD

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Pg. 2/...

Biomedical Research Ethics Committee

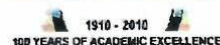
Professor J Tsoka-Gwegweni (Chair)

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 Durban Campus
  Edgewood
  Howard College
  Medical School
  Pietermaritzburg
  Westville

2. Ethics approval for the study from NIMHANS



National Institute of Mental Health & Neuro Sciences (Deemed University), Bangalore - 29

ರಾಷ್ಟ್ರೀಯ ಮಾನಸಿಕ ಸ್ವಾಸ್ಥ್ಯ ಉಪ-ವಿಜ್ಞಾನ ಸಂಸ್ಥಾನ (ಮಾನಕ ವಿಶ್ವವಿದ್ಯಾಲಯ) ಬೆಂಗಳೂರು - 29
ರಾಷ್ಟ್ರೀಯ ಮಾನಸಿಕ ಆರೋಗ್ಯ ಮತ್ತು ನರ ವಿಜ್ಞಾನ ಸಂಸ್ಥೆ (ಪರಿಗಣಿತ ವಿಶ್ವವಿದ್ಯಾಲಯ), ಬೆಂಗಳೂರು - 29

Ref.: No. NIMH/DO/Ethics Sub-committee/30//2016

Date : Date: 7.8.16

Dr. M Jayaram
Senior Professor of Speech Pathology & Audiology
Dean - Neurosciences & Member Secretary
NIMHANS Ethics Committee

Off: 91 - 80 - 26995569 / 5850
Fax: 91 - 80 - 26564830
email: jayaram@nimhans.ac.in
drmjay16@gmail.com

Through HoD and Guide

1. **Name of the investigator:** Mrs. Ayanikalath Narayanan Sona,
Ph.D Scholar, Speech Language Pathology,
College of Health Sciences, South Africa
(with a joint guide from NIMHANS)
2. **Reference number of the investigator:** Letter dated 17.06.2016
3. **Title of the proposal submitted for ethical clearance** Ph.D Thesis Protocol
"Developing and evaluating the effectiveness of an ecologically valid telerehabilitation system for assessment and primary management of adult neurogenic dysphagia in India".
4. **Nature of the proposal submitted for ethical clearance** Ph.D Thesis Protocol
5. **Date of Ethics Sub-Committee meeting:** 27th June, 2016
6. **Members of the Ethics Sub-Committee who Reviewed and recommended the proposal:** Dr. M. Jayaram, Dean (Neurosciences),
Chairman, (Neurosciences),
Dr. S.K. Chaturvedi, Dean (Behavioural Sciences), Member,
Dr. G. Gururaj, Professor of Epidemiology, Member

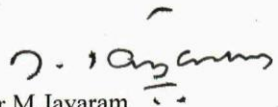
7 Members of the NIMHANS Ethics Committee who Reviewed and recommended the proposal:

- | | | | |
|-----|--|---|------------------|
| 1. | Dr. Anura Vishwanath Kurpad, (MBBS,MD),
Professor of Physiology | : | Chairman |
| 2. | Dr. Rajaram Subbian, (Social Scientist) | : | Member |
| 3. | Dr. Denis Xavier, Professor of Pharmacology | : | Member |
| 4. | Dr. Ashok R. Patil, Professor of Law (Legal Expert) | : | Member |
| 5. | Dr. Rita Christopher, Professor of Neurochemistry | : | Member |
| 6. | Dr. N. Shivashankar, Professor of Speech
Pathology & Audiology | : | Member |
| 7. | Dr. H. Uma, Professor of Clinical Psychology | : | Member |
| 8. | Dr. Pratima Murthy, Professor of Psychiatry | : | Member |
| 9. | Dr. Pramod Kumar Pal, Professor of Neurology | : | Member |
| 10. | Dr. V. Ravi, Dean (Basic Sciences) | : | Member |
| 11. | Dr. M. Jayaram, Dean (Neurosciences) | : | Member |
| 12. | Dr SK Chaturvedi, Dean (Behr. Sciences) | : | Member Secretary |
- 7. Date of the meeting of the Ethics Committee** 2nd July 2016

**8 Clear statement of the decision reached:
Decision of the IEC:**

The Ph.D thesis protocol and study related documents are approved with respect to ethical aspects.

Work can be initiated by the candidate only after obtaining approval from the Biomedical Research Ethics Committee of the candidate's University in South Africa


Dr M Jayaram
Member-Secretary of the NIMHANS Ethics
Committee (Basic and Neurosciences)
Chairman-Sub-committee (Neurosciences)

Dr. M. Jayaram, Ph.D
Senior Professor and Head -
Speech Pathology & Audiology
Dean - Faculty of Neurosciences
National Institute of Mental Health & Neurosciences
Bangalore - 560 029.

3. Study One interview schedule



TR Personnel Semi Structured Interview

NAME:

ORGANIZATION:

DESIGNATION:

AREA OF SPECIALIZATION:

DATE OF INTERVIEW:

FOCUS	SEMI STRUCTURED INTERVIEW QUESTIONS
A. Current status of TR in India	1. Could you tell me about the current status of TR in India? 2. How often is TR used in your organization? 3. Are follow ups possible after an assessment with TR?
B. Benefits of using TR in India	4. What are the benefits of using TR in India? 5. Is TR able to improve the accessibility of patients to doctors? 6. Is TR able to improve accessibility to underserved areas in India?
C. Changes made to make TR ecologically valid	7. Describe the changes that needed to be made in TR in India, when compared to the TR in economically developed countries? 8. Could you describe any major challenges you have faced in implementing TR in the community? 9. Could you provide your comments regarding the below

	<p>variables that may affect ecological validity of TR when used/adapted for India</p> <ul style="list-style-type: none"> a) Internet connection b) Internet bandwidth c) Availability of computers and other accessories d) Human interface with technology e) Personnel required to use TR f) Training required for personnel to use TR <p>10. Are there any more variables that could affect the ecological validity of the TR system?</p>
D. Perceptions or attitudes towards TR	<p>11. How acceptable is this new method by professionals in India?</p> <p>12. How acceptable is TR by patients/caregivers in India?</p>
E. Opinion regarding TR for speech language therapy in India	<p>13. What is your opinion about the feasibility of providing speech language therapy using TR in India?</p> <p>14. Based on your experience in TR, in what ways can the TR system be modified to be used for speech language therapy management in India?</p>

4. Study One Information Sheet and Consent form



Information sheet and consent form for semi structured interview of TR personnel in India

TITLE OF THE RESEARCH PROJECT: Investigation of the effectiveness of an ecologically valid Telerehabilitation system for the assessment and primary management of adult neurogenic dysphagia in a resource constrained country

REFERENCE NUMBER:

PRINCIPAL INVESTIGATOR: Sona Narayanan Ayanikalath

ADDRESS: P O Box. 767406, Abu Dhabi, UAE

CONTACT NUMBER: 00971506131041

Date:

Dear Sir/Madam

My name is Sona Narayanan Ayanikalath, and I am a PhD student at the University of KwaZulu Natal in South Africa. The study I wish to conduct for my Doctoral thesis involves investigating the effectiveness of an ecologically valid Telerehabilitation for the assessment and primary management of adult neurogenic dysphagia in a resource constrained country. This project will be conducted under the supervision of Professor Mershen Pillay (University of KwaZulu Natal, South Africa) and Dr. M. Jayaram (National Institute of Mental Health and Neurosciences, India).

I will be recruiting medical and/or allied health professional with experience in telemedicine from your esteemed institution as participant for the study. He/she will be involved in a semi structured interview to raise and discuss their opinions regarding the development and use of an ecologically valid TR system for a resource constrained country. This procedure will help to explore insights about TR in resource constrained countries that have otherwise remained hidden.

In the event of any problems or concerns/questions you may contact the researcher at sonanarayanan4@gmail.com or the UKZN Biomedical Research Ethics Committee, contact details as follows:

BIOMEDICAL RESEARCH ETHICS ADMINISTRATION

Research Office, Westville Campus

Govan Mbeki Building

Private Bag X 54001

Durban 4000

KwaZulu-Natal, SOUTH AFRICA

Tel: 27 31 2604769 - Fax: 27 31 2604609

Email: BREC@ukzn.ac.za

Your participation in this study is voluntary and you may withdraw participation at any point, and that in the event of refusal/withdrawal of participation the participants will not incur penalty. All identifiable information will be coded prior to analysis of the information to maintain confidentiality. The information is accessible only to the researcher, the supervisor of the study project and the relevant medical professionals involved in your rehabilitation process. Any disclosure of information will only be with your permission, except as required by law. In any publication, information will be provided in such a way that you cannot be identified. You will be assigned a participant number for this project that will be used to describe your results

and personal information in any publications. Only the research team will have access to your name and demographic details.

CONSENT (Edit as required)

I (Name) have been informed about the study entitled (provide details) by (provide name of researcher/fieldworker). I understand the purpose and procedures of the study. I have been given an opportunity to answer questions about the study and have had answers to my satisfaction. I declare that my participation in this study is entirely voluntary and that I may withdraw at any time. If I have any further questions/concerns or queries related to the study I understand that I may contact the researcher at (provide details). If I have any questions or concerns about my rights as a study participant, or if I am concerned about an aspect of the study or the researchers then I may contact:

BIOMEDICAL RESEARCH ETHICS ADMINISTRATION

Research Office, Westville Campus
Govan Mbeki Building
Private Bag X 54001
Durban 4000
KwaZulu-Natal, SOUTH AFRICA
Tel: 27 31 2604769 - Fax: 27 31 2604609
Email: BREC@ukzn.ac.za

Signature of Participant

Date

Signature of Witness

Date

(Where applicable)

Signature of Translator

Date

(Where applicable)

5. Study Two Clinical Swallow Evaluation Proforma (Sharma, 2012)

TELEREHABILITATION APPLICATION FOR THE MANAGEMENT OF SWALLOWING DISORDERS

CLINICAL SWALLOWING EVALUATION PROFORMA

Patient Name:		Ref. Ward:		No.:	
D.O.B:		Diagnosis:			
Current Diet Status:					
NPO	Food: Pureed / Minced & Moist / Soft / Regular		Fluids: Extremely thick (Pureed) / Moderately Thick / Mildly Thick / Thin-Water		
Alertness: Alert / Not Fully Alert / Non-responsive compliant			Comprehension: Able to Comprehend / Partial Comprehension / Non-compliant		
Pulse Oximeter Reading:					
Oral Motor Assessment:	Normal (1)	Mild Impairment (2)	Moderate Impairment (3)	Moderate-Severe Impairment (4)	Severe Impairment (5)
Jaw symmetry (rest)					
Squeeze eyes closed					
Raise eyebrows					
Open/close mouth (x3)					
Open/close mouth against resistance					
Smile wide					
Puff cheeks (lip seal)					
Pucker					
Smile wide-Pucker with speed					
“Ahh” (nasality)					
“Ahh” (breath support)					

**DIET
RECOMMENDATION**

NPO	
MODIFIED FOOD / FLUIDS	
Maintain Present Diet	
Change Diet	



Fluids :	Water / Thin	
	Mildly Thick	
	Moderately Thick	
	Extremely thick (Pureed)	
Fluids: Upgrade / Downgrade		

(DOSS Rating)

Foods :	Regular	
	Soft	
	Minced & Moist	
	Pureed	
Foods: Upgrade / Downgrade		

DYSPHAGIA SEVERITY

Level 7
Level 6
Level 5
Level 4
Level 3
Level 2
Level 1

NORMAL FOOD / FLUIDS	
--	--

**NEED FOR FEEDING
ASSISTANCE?**

Yes		No	
-----	--	----	--

Type of assistance required:

NEED FOR ROUTINE ORAL CARE?

Yes		No	
-----	--	----	--

NEED FOR INSTRUMENTAL EVALUATION OF SWALLOWING:

MBS	Yes		No	
	Urgent (Cat. 1)			
	Semi-urgent (Cat. 2)			
	Non-urgent (Cat. 3)			

FEES	Yes		No	
	Urgent (Cat. 1)			
	Semi-urgent (Cat. 2)			
	Non-urgent (Cat. 3)			

NEEDS REFERRAL TO ANOTHER MEDICAL PROFESSIONAL?

Yes
No

Who?

SPEECH PATHOLOGY REVIEW:

Review in:	1-2 days	
	3-4 days	
	≥ 1 week	
	≥ 2 weeks	
	≥ 1 month	
	≥ 3 months	

Additional Comments:

DOSS -DYSPHAGIA OUTCOME AND SEVERITY SCALE

Full per-oral nutrition (P.O): Normal diet

Level 7: Normal in all situations

Normal diet

No strategies or extra time needed

Level 6: Within functional limits/modified independence

Normal diet, functional swallows

Patient may have mild oral or pharyngeal delay, retention or trace epiglottal undercoating but independently and spontaneously compensates/clears

May need extra time for meal

Have no aspiration or penetration across consistencies

Full P.O: Modified diet and/or independence

Level 5: Mild dysphagia: Distant supervision may need one diet consistency restricted

May exhibit one or more of the following

Aspiration of thin liquids only but with strong reflexive cough to clear completely

Airway penetration midway to cords with one or more consistency or to cords with one consistency but clears spontaneously

Retention in pharynx that is cleared spontaneously

Mild oral dysphagia with reduced mastication and/or oral retention that is cleared spontaneously

Level 4: Mild–moderate dysphagia: Intermittent supervision/cueing, one or two consistencies restricted

May exhibit one or more of the following

Retention in pharynx cleared with cue

Retention in the oral cavity that is cleared with cue

Aspiration with one consistency, with weak or no reflexive cough

Or airway penetration to the level of the vocal cords with cough with two consistencies
 Or airway penetration to the level of the vocal cords without cough with one consistency

Level 3: Moderate dysphagia: Total assist, supervision, or strategies, two or more diet consistencies restricted

May exhibit one or more of the following

Moderate retention in pharynx, cleared with cue

Moderate retention in oral cavity, cleared with cue

Airway penetration to the level of the vocal cords without cough with two or more consistencies

Or aspiration with two consistencies, with weak or no reflexive cough

Or aspiration with one consistency, no cough and airway penetration to cords with one, no cough

Non-oral nutrition necessary

Level 2: Moderately severe dysphagia: Maximum assistance or use of strategies with partial P.O. only (tolerates at least one consistency safely with total use of strategies)

May exhibit one or more of the following

Severe retention in pharynx, unable to clear or needs multiple cues

Severe oral stage bolus loss or retention, unable to clear or needs multiple cues

Aspiration with two or more consistencies, no reflexive cough, weak volitional cough

Or aspiration with one or more consistency, no cough and airway penetration to cords with one or more consistency, no cough

Level 1: Severe dysphagia: NPO: Unable to tolerate any P.O. safely

May exhibit one or more of the following

Severe retention in pharynx, unable to clear

Severe oral stage bolus loss or retention, unable to clear

Silent aspiration with two or more consistencies, non-functional volitional cough

Or unable to achieve swallow

Speech Pathology for MBS/FEES Clinic Prioritization

Category One: Urgent – Requiring appointment within 5 working days
<p>1.a Suspected silent aspiration (+/- confirmed chest infection)</p> <p>1.b Dysphagia with risk of malnutrition/dehydration due to suspected anatomical abnormality, suspected malignancy/idiopathic pain, significant/unexplained weight loss.</p> <p>1.c Clinical dysphagia, NBM with no alternative feeding in place</p> <p>1.d Requiring MBS prior to discharge where no regional MBS facilities are available.</p>
Category Two: Semi Urgent – Schedule appointment when next clinic available
<p>2.a Documented aspiration pneumonia where swallow can be managed clinically</p> <p>2.b Clinical dysphagia, NBM with alternative feeding</p> <p>2.c Clinical dysphagia, stable on a diet</p> <p>2.d MBS required post swallowing rehabilitation</p> <p>2.e Air Insufflation Test post TEP. No voice, requiring investigation.</p> <p>2.f MBS required for patient compliance – clinical evidence to show high risk of aspiration</p>
Category Three: Non Urgent
<p>3.a Long-standing dysphagia where no change in management is anticipated. Review of dysphagia status only +/- discharge planning.</p> <p>3.b Air Insufflation Test prior to consideration of secondary TEP.</p>

6. Study Two Information Sheet and Consent form for simulated patient



Information sheet and consent form for TR study participants (simulated patient)

TITLE OF THE RESEARCH PROJECT: Investigation of the effectiveness of an ecologically valid Telerehabilitation system for the assessment and primary management of adult neurogenic dysphagia in a resource constrained country

REFERENCE NUMBER:

PRINCIPAL INVESTIGATOR: Sona Narayanan Ayanikalath

ADDRESS: P O Box. 767406, Abu Dhabi, UAE

CONTACT NUMBER: 00971506131041

Date:

Dear Sir/Madam

My name is Sona Narayanan Ayanikalath, and I am a PhD student at the University of KwaZulu Natal in South Africa. You are being invited to participate in the study - Investigating the effectiveness of an ecologically valid telerehabilitation for assessment and primary management of adult neurogenic dysphagia in a resource constrained country. This project will be conducted under the supervision of Professor Mershen Pillay (University of KwaZulu Natal, South Africa) and Dr. M. Jayaram (National Institute of Mental Health and Neurosciences, India).

The aim and purpose of this study is to study if TR can be used effectively in the assessment and primary management of neurogenic dysphagia. This study is expected to enrol five simulated actors. As a simulated actor, you should act like a patient with dysphagia. The

training for the same will be provided to you before the study. It will involve the use of telerehabilitation in the assessment and primary management of neurogenic dysphagia. The procedure will take approximately one and half hour. The assessment session will be video-recorded but no personal information will be revealed to anyone other than the researchers concerned. Video-recording the session will assist the researchers to assess the accuracy of online swallowing assessment and whether it can be carried out with patients living in remote areas. The study does not involve the any risks and/or discomforts. I hope that the study will be able to prove that the TR system developed as a part of this study is ecologically valid and is effective in the assessment and primary management of neurogenic dysphagia. In the event of any problems or concerns/questions you may contact the researcher at sonanarayanan4@gmail.com or the UKZN Biomedical Research Ethics Committee, contact details as follows:

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Research Office, Westville Campus
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 Tel: 27 31 2604769 - Fax: 27 31 2604609
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Your participation in this study is voluntary and you may withdraw participation at any point, and that in the event of refusal/withdrawal of participation the participants will not incur penalty. All identifiable information will be coded prior to analysis of the information to maintain confidentiality. The information is accessible only to the researcher, the supervisor of the study project and the relevant medical professionals involved in your rehabilitation process. Any disclosure of information will only be with your permission, except as required by law. In any publication, information will be provided in such a way that you cannot be identified. You will be assigned a participant number for this project that will be used to describe your results

and personal information in any publications. Only the research team will have access to your name and demographic details.

CONSENT (Edit as required)

I (Name) have been informed about the study entitled (provide details) by (provide name of researcher/fieldworker). I understand the purpose and procedures of the study. I have been given an opportunity to answer questions about the study and have had answers to my satisfaction. I declare that my participation in this study is entirely voluntary and that I may withdraw at any time without affecting any treatment or care that I would usually be entitled to. I have been informed about any available compensation or medical treatment if injury occurs to me as a result of study related procedures. If I have any further questions/concerns or queries related to the study I understand that I may contact the researcher at (provide details). If I have any questions or concerns about my rights as a study participant, or if I am concerned about an aspect of the study or the researchers then I may contact:

BIOMEDICAL RESEARCH ETHICS ADMINISTRATION

Research Office, Westville Campus
 Govan Mbeki Building
 Private Bag X 54001
 Durban 4000
 KwaZulu-Natal, SOUTH AFRICA
 Tel: 27 31 2604769 - Fax: 27 31 2604609
 Email: BREC@ukzn.ac.za

 Signature of Participant

 Date

 Signature of Witness
 (Where applicable)

 Date

 Signature of Translator
 (Where applicable)

 Date

7. Study Two Information Sheet and Consent form for speech language pathologist



Information sheet and consent form for TR study participants (Speech Language Pathologist)

TITLE OF THE RESEARCH PROJECT: Investigation of the effectiveness of an ecologically valid Telerehabilitation system for the assessment and primary management of adult neurogenic dysphagia in a resource constrained country

REFERENCE NUMBER:

PRINCIPAL INVESTIGATOR: Sona Narayanan Ayanikalath

ADDRESS: P O Box. 767406, Abu Dhabi, UAE

CONTACT NUMBER: 00971506131041

Date:

Dear Sir/Madam

My name is Sona Narayanan Ayanikalath, and I am a PhD student at the University of KwaZulu Natal in South Africa. You are being invited to participate in the study - Investigating the effectiveness of an ecologically valid telerehabilitation for assessment and primary management of adult neurogenic dysphagia in a resource constrained country. This project will be conducted under the supervision of Professor Mershen Pillay (University of KwaZulu Natal, South Africa) and Dr. M. Jayaram (National Institute of Mental Health and Neurosciences, India).

The aim and purpose of this study is to evaluate if TR can be used effectively in the assessment and primary management of neurogenic dysphagia. This study is expected to enrol

five dysphagia trained speech language pathologists in India. It will involve the use of telerehabilitation in the assessment and primary management of neurogenic dysphagia. You should do a face to face clinical swallow assessment of the simulated patients. The procedure will take approximately one and half hours per patient. The assessment session will be video-recorded but no personal information will be revealed to anyone other than the researchers concerned. Video-recording the session will assist the researchers to assess the accuracy of online swallowing assessment and whether it can be carried out with patients living in remote areas. The study does not involve the any risks and/or discomforts. I hope that the study will be able to prove that the TR system developed as a part of this study is ecologically valid and is effective in the assessment and primary management of neurogenic dysphagia. In the event of any problems or concerns/questions you may contact the researcher at sonanarayanan4@gmail.com or the UKZN Biomedical Research Ethics Committee, contact details as follows:

BIOMEDICAL RESEARCH ETHICS ADMINISTRATION

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 Private Bag X 54001
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 KwaZulu-Natal, SOUTH AFRICA
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 Email: BREC@ukzn.ac.za

Your participation in this study is voluntary and you may withdraw participation at any point, and that in the event of refusal/withdrawal of participation the participants will not incur penalty. All identifiable information will be coded prior to analysis of the information to maintain confidentiality. The information is accessible only to the researcher, the supervisor of the research project and the relevant medical professionals involved in your rehabilitation process. Any disclosure of information will only be with your permission, except as required by law. In any publication, information will be provided in such a way that you cannot be identified.

You will be assigned a participant number for this project that will be used to describe your results and personal information in any publications. Only the research team will have access to your name and demographic details.

CONSENT (Edit as required)

I (Name) have been informed about the study entitled (provide details) by (provide name of researcher/fieldworker). I understand the purpose and procedures of the study. I have been given an opportunity to answer questions about the study and have had answers to my satisfaction. I declare that my participation in this study is entirely voluntary and that I may withdraw at any time without affecting any treatment or care that I would usually be entitled to. I have been informed about any available compensation or medical treatment if injury occurs to me as a result of study-related procedures. If I have any further questions/concerns or queries related to the study I understand that I may contact the researcher at (provide details). If I have any questions or concerns about my rights as a study participant, or if I am concerned about an aspect of the study or the researchers then I may contact:

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 Signature of Participant

 Date

 Signature of Witness
 (Where applicable)

 Date

 Signature of Translator
 (Where applicable)

 Date