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# RESEARCH REPORT

Submitted to the University of Cape Town.

In fulfilment of the requirements for the degree

**MSc in Speech-Language Pathology (by dissertation only)**

How can health literacy and client recall/memory of clinical information be maximised in the field of Speech-Language Pathology?

An exploratory study of clients and therapists in the Western Cape

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**Ethical approval letter**

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## Glossary

**Airtime** – Refers to the actual time that is spent talking on a wireless or mobile phone (Morefocus Group Inc., 2008).

**Aspiration pneumonia** – Aspiration of foods and liquids into the lungs, which has led to respiratory tract infections (Cherney, 1994; Low, Wyles, Wilkinson, Sainsbury, 2001).

**Bluetooth** – Is a wireless connection that enables electronic devices to exchange information (Morefocus Group Inc., 2008).

**Case study (single-subject design)** - Single-subject (case study) design is the use of systematic methods for applying interventions and documenting their effects repeatedly in single individuals over a period of time (Maxwell & Satake, 2006).

**CD-ROM** - The Compact Disc-Read Only Memory (CD-ROM), a CD with a large data storage capacity (Doak, Doak & Root, 1996).

**Cerebral palsy (CP)** – Cerebral Palsy describes a group of disorders in the development of posture and movement which causes activity limitations that are ascribed to non-progressive disturbances that occurred in the brain during prenatal development, at birth or during the post-natal period (Arvedson & Brodsky, 2002).

**Cerebrovascular accident (CVA)** – A sudden interruption to the flow of blood to the brain. It may be due to an ischemic attack (blocking of blood vessels) or due to a haemorrhage (bursting of blood vessels) (Chapey, 2001).

**Client recall/memory** – Client recall/memory is the retention of information, both short- and long-term. A combination of comprehension, working memory, long-term and prospective memory is necessary for adherence to recommendations (Park, Morrell, Frieske & Kincaid, 1992).

**Compliance (non-compliance/low adherence)** – “The extent to which a client’s behaviour (in terms of taking medication, following a diet, modifying habits, or attending clinics) coincides with medical or health advice” (McDonald, Garg & Haynes, 2002, p. 2868)

**Degenerative disease** – Is a disease that progressively deteriorates (Chapey, 2001).

**Dysarthria** – “It is a collective name for a group of speech disorders resulting from disturbances in muscular control over the speech mechanism due to damage to the central or peripheral nervous system. Problems in communication are due to paralysis, weakness or incoordination of the speech musculature” (Darley, Aronson & Brown, 1975, p. 246).

**Effectiveness** – “Producing a desired or intended result” (Compact Oxford English Dictionary, 2000, p. 348).

**Efficacy** – “The ability to produce a desired or intended result” (Compact Oxford English Dictionary, 2000, p. 348).

**Efficiency** – “The state or quality of being efficient” (Compact Oxford English Dictionary, 2000, p. 348).

**ENT (Otolaryngologist)** – “Physician specialising in ear, nose and throat pathologies” (Compact Oxford English Dictionary, 2000, p. 364).

**False vocal fold adduction** – Attempting phonation while squeezing the false vocal folds situated above the vocal folds (Schwartz, 2004).

**Fluency** (also know as “stuttering”) – It is a communication disorder in which the smooth and forward flow of speech is disrupted (Guitar, 1998).

**Focus group** - A focus group is a group of people, who share a similar kind of experience, but they do not “naturally” represent an existing social group (Kelly, 2006a).

**Gastro-oesophageal reflux disease (GORD)** – Recurrent regurgitation of stomach contents (Arvedson & Brodsky, 2002).

**Health literacy** – “The degree to which individuals have the capacity to obtain, process, and understand basic health information and the services needed to make appropriate health decisions” (Institute of Medicine, 2007, p.1).

**i-pod** – Is a portable device on which audiofiles can be stored and played (Wallener, 2003).

**Larynx** – Is the organ that forms an air passage to the lungs and also contains the vocal cords (also known as the “voice box”) (Colton & Casper, 1996).

**Laryngectomy** - In the case where cancer of the larynx has advanced to a stage where it has to be removed surgically, that client becomes a person with a laryngectomy (i.e. their larynx is entirely removed) (Engelbrecht, Van der Merwe & Pretorius, 2006; Silver, 1991).

**MMS (Multimedia Messaging Services)** – It allows a person to send and receive messages that contain more than text (e.g. graphics, photographs, audio and video clips) (Federal Wireless Communications, 2005).

**Mobile Dynamic Frequently Asked Questions (M-DFAQ system)** - It is an internet-based SMS service where a 5 digit number is used to send a message to a website at low cost (i.e. 1 or 2 cents). The message is displayed on this site and whoever the message was sent to can read it, reply and send it off to the sender’s phone via SMS, also at no cost (Ng’ambi, 2005).

**Neurogenic language disorders** – Neurogenic language disorders result from illnesses, accidents or progressive diseases that cause brain damage. They can negatively affect a patient’s communicative and cognitive well-being (Murray & Clark, 2006).

**Orogastric / naso-gastric tube** – Tube through which food is directed straight into the stomach either through the mouth or through the nose (Arvedson & Brodsky, 2002).

**PC** – Abbreviated term for personal computer (WordNet Search, 2009a).

**SMS (Short Message Service)** – Abbreviation for a text message feature on mobile phones (Web Resources, 2009).

**Socio-economic** – “Relating to or concerned with the interaction of social and economic factors” (Compact Oxford English Dictionary, 2000, p. 1093).

**Spontaneous recovery** – When the body recovers from brain damage, some patients will regain former skills (e.g. talking, walking). This improvement may occur within days and last for months. However, it seldom produces complete return of functions (Nevada Care Connection, 2009).

**Traumatic brain injury (TBI)** – Injury to the brain as a result of an accident (e.g. motor vehicle accident, any trauma to the head) (Arvedson & Brodsky, 2002).

**Treacher Collins syndrome** – A syndrome transmitted through an inheritance pattern. Characteristics include underdevelopment of bones, defect of the lower eyelids, and deformed outer and middle ears (Arvedson & Brodsky, 2002).

**USB (Universal Serial Bus)** – Is a type of connection that is used to connect external devices to a computer (e.g. printers, cameras) (BBC Home, 2009).

**Voice disorders** - Symptoms range from hoarseness, vocal fatigue, and absence of the voice to strained and strangled voice (Schwartz, 2004).

**Voicemail** – A voicemail is a digital system for recording voice messages (WordNet Search, 2009b).

**Web cam** – a digital camera designed to take digital photographs and transmit them over the internet (WordNet Search, 2009c).

## **Abstract**

The **aims** of this study were to (a) explore health literacy and information recall/memory of clients receiving Speech-Language Pathology treatment in Cape Town, and (b) to explore ways of maximising these factors in clients with dysphagia, voice disorders (including laryngectomies) and cleft lip and/or palate.

The **method** comprised of an exploratory, inductive design, with qualitative methods of data gathering. The participants were (a) Speech-Language Pathologists, (b) clients, who had received Speech-Language Pathology treatment in the past, and (c) clients who were receiving Speech-Language Pathology treatment for the above-mentioned disorders at the time of this research. There were three phases in this study. In phase 1, data was gathered through focus group discussions to explore SLPs' and clients' views on health literacy and client recall/memory and how these might be maximised. In phase 2, the data from phase 1 was used to trial three combined strategies (audio-recorded information, "please call me" SMS and telephonic follow-up) in four cases in order to maximise health literacy and client recall/memory of clinical information. In phase 3, the outcomes of the strategies were evaluated through semi-structured exploratory interviews from both the SLP's and client's perspective. Data was analysed qualitatively.

The **results** provided insight into various factors which played a role in clients' compliance with treatment regimes. These related to the client and the SLP; health literacy and recall; factors between SLPs and clients, and the clinical environment. SLPs utilised various, mostly low tech strategies to overcome some of the issues around health literacy and client recall/memory of clinical information during consultations. Considering the advantages and disadvantages of these strategies, the researcher proposed a combination of high tech strategies which proved to be of assistance in all four cases – with no one solution or universal tool for maximising health literacy and recall appropriate for all. Client-specific, cultural, environmental, time and resource factors need to be considered for strategies to be effective and efficient.

In **conclusion**, there is a need to evaluate the long-term effectiveness of the combined strategies across a wider population, at different stages of rehabilitation and in diverse contexts. Further challenges for SLPs will be to manage barriers such as clients' varying levels of literacy, motivation, insight and problem-solving skills. Additional barriers include the lack of support from families, trained interpreters as well as funds and resources. Limitations of the study and implications were discussed.

**Key words:** health literacy, recall/memory, strategies, compliance, Speech-Language Pathology treatment

# **Chapter 1: Introduction and Literature Review**

This thesis is organised into five chapters. In chapter one, the main topic of the thesis is introduced and discussed, based on a literature review. Chapter two outlines the research methodology applied to three phases conducted in this study. In chapters three and four results are reported and discussed after which chapter five outlines implications and limitations of this study as well as recommendations for future research and a conclusion.

## **1.1. Introduction**

Clients in the healthcare sector frequently struggle to understand and remember details of clinical information and reasons underlying their treatment (Morrell, Park & Poon, 1990; Zagaria, 2006). As a result, they often do not adhere to clinical instructions and recommendations, which contributes to a reduction in the effectiveness and efficiency of healthcare interventions (Bandura, 2002; Kessels, 2003).

However,

“why would someone who has gone to the trouble and expense of (a) seeking out a physician, (b) undergoing arduous or uncomfortable tests and other diagnostic procedures, and (c) purchasing drugs and devices on the advice of the physician, then fail to follow the recommendations?” (Stone, 1979, p. 1).

Various healthcare professionals have speculated about this issue and there is consensus that, in order to support clients in managing their own health, they need to be provided with a documented record of client-specific clinical information (Kreuter, Bull, Clark & Oswald, 1999; Osborne, 2008b & 2008c; Santo, Laizner & Shohet, 2005; Weiss & Coyne, 1997). This poses specific challenges in people who have low literacy skills as they have fewer means to improve their health literacy skills (e.g. through the internet) or review health advice because they cannot read written materials (e.g. pamphlets or lists with instructions to execute certain treatments).

The field of Speech-Language Pathology covers various areas of expertise ranging from managing speech-language and literacy difficulties in children to adult and paediatric dysphagia, motor speech disorders (dysarthria) and neurogenic language disorders in adults, voice disorders, children with cleft lip and/or palate, laryngectomies and fluency disorders. Very little research has been conducted

with regards to health literacy and patient or caregiver<sup>1</sup> recall/memory in the field of Speech-Language Pathology (Hester & Benitez-McCrary, 2006). However, Speech-Language Pathologists<sup>2</sup> frequently provide vast amounts of information that clients need to understand, apply and review in order to manage their (or their child's) health. Thus, there is a need for further investigation to attain insight into (a) the presenting issues around clients' health literacy and recall/memory of information and (b) how these can be overcome.

## 1.2. Health literacy: a background

Health literacy<sup>3</sup> is defined as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and the services needed to make appropriate health decisions” (Institute of Medicine (IOM), 2007, p.1). It is “the wide range of skills and competencies that people develop over their lifetimes to seek out, comprehend, evaluate and use health information and concepts to make informed choices, reduce health risks, and increase quality of life” (Zarcadoolas, Pleasant & Greer, 2006, p. 55). A health literate person can recognise a need for health information, identify possible sources of information, evaluate that health information for quality and reliability and then use it to assist in making health decisions (Flemming, 2007).

While writing, reading and numeracy skills form a basis for good health literacy skills, many other abilities are equally important. These include speaking and listening well, having adequate background information about health, reasoning and solving problems effectively, as well as being able to advocate for oneself in the healthcare system (IOM, 2004). This is also known as “functional literacy” (Underwood, 2002). The term *health literacy* does not distinguish between health information in print, spoken language (i.e. speech and speech comprehension) or other forms of written symbols (i.e. numbers, pictures, graphics and other visual representations) (Zarcadoolas et al., 2006).

Alternatively, *low* health literacy is the inability to read, understand, and act accordingly on even the most basic health information and instructions (Flemming, 2007). For example, professionals working in the field of paediatrics may face difficulties in delivering useful preventative guidance (e.g. the need for immunization) as well as health education to caregivers with low health literacy

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<sup>1</sup> Hereinafter patients and/or their caregivers will be referred to collectively as clients.

<sup>2</sup> Hereinafter the term Speech-Language Pathologist(s) will be abbreviated to SLP(s).

<sup>3</sup> In this thesis, the terms ‘knowledge’ and ‘understanding’ are used synonymously with ‘health literacy’.

skills (Sanders, Thompson & Wilkinson, 2007). In Speech-Language Pathology this could translate into clients not understanding the techniques they need to employ when feeding a child with feeding and swallowing difficulties.

Clients with low health and general literacy skills may have poorer health, higher expenses for healthcare and a higher rate of hospitalisations than those clients with better-developed health and general literacy skills (Ross, 2007; Weiss, Blanchard & McGee, 1994; Weiss, Hart, McGee & D'Estelle, 1992). These particular clients may also experience difficulties with completing medical forms as well as understanding medication labels, verbal instructions, consent forms and brochures, thus reducing a client's self-efficacy for preventive care practices and disease self-management as well as compliance to treatment regimes (Arias, 2006; Baker, Parker, Williams, et al., 1996; Bandura, 2002; Murphy-Knoll, 2007; Tattersall, Butow, Griffin & Dunn, 1994; Zagaria, 2006).

Health literacy is affected by aspects such as demographic, socio-political, cultural and psychosocial factors (Helman, 1994; Zarcadoolas et al., 2006). The above is true regardless of socio-economic status (Williams, Baker, Parker & Nurss, 1998). People can have years of education and high functional literacy (reading, writing and numeracy skills), but can still have limited health literacy skills (Glassman, 2007). Health literacy skills are also not bound to race or age (Baker, Parker, Williams & Clark, 1998; Glassman, 2007) even though the Interagency Coordinating Council (2002) stated that 80% of the population aged 60 years and older in the United States alone have insufficient health literacy skills.

There are various challenges to health literacy and causes for clients refraining from asking questions and making their needs known. Firstly, clients mistrusting and feeling inferior to health professionals, while being overwhelmed by responsibilities in their own health management impact their readiness to make their needs known (Zagaria, 2006). Secondly, the complexity of written and verbal health information and the shortage of health information in languages other than English make it difficult for individuals with low general literacy skills and language differences to effectively communicate in healthcare (Zarcadoolas et al., 2006). Individuals with speech, language, visual, hearing and intellectual disabilities, experience even greater challenges when they need to apply high-level health literacy skills (Hester & Benitez-McCrary, 2006).

In South Africa, 15 million people cannot read or write and it is estimated that one in every five South Africans, who is over the age of 20 years, has not received formal education (Breier & Sait, 1997; Nelson Mandela Foundation, 2004; Statistics South Africa, 2001). Furthermore, illiteracy varies from 27 % in South African urban areas to 50 % in rural areas (Lecoko, Dowse & Ehlers, 2002). It has also been observed that there is generally a high percentage of people who cannot read above a fourth-grade reading level even though they have completed a higher scholastic grade (Davis, Crouch, Wills, Miller & Abdehou, 1990). In the healthcare sector and especially in Speech-Language Pathology where written information is frequently provided, this may lead to extreme frustration on the part of the client (Lee, 1999; Louw, Shibambu & Roemer, 2006). Health professionals often overestimate their clients' literacy skills which may hinder successful client-provider communication (Kelly & Haidet, 2007) and even when health professionals have worked with clients (who have low literacy skills) for years, they are frequently surprised at the poor reading skills of some of their most articulate clients (Parker, Williams & Davis, 1999).

Some studies highlighted the issue of assessing clients' levels of literacy with the intention of accommodating their needs by using appropriate materials during consultations and when providing health information (Baker, Parker, Williams, et al., 1996; Chew, Bradley & Boyko, 2004; Doak, Doak, Friedell & Meade, 1998; Kelly & Haidet, 2007). Yin, Forbis and Dreyer (2007) acknowledge that screening clients for low literacy is not clear-cut, and simply asking a person for their level of education does not accurately assess their literacy level. This is mainly because clients with low literacy skills feel embarrassed and may develop compensatory coping strategies (Baker, Parker, Williams, et al., 1996; Moon, Cheng, Patel, Baumhaft & Scheidt, 1998; Parikh, Parker, Nurss, Baker & Williams, 1996). For example, clients will either not come for consultations unless they have someone who can read, attend the consultation with them or they will rely largely on oral explanations and demonstrations of tasks (Parikh et al., 1996). Even though it is of benefit that clients can rely on oral explanations and demonstrations of tasks during consultations, these are not strategies which allow for review of information once they are at home.

There remains uncertainty about how best to identify those clients needing support to become health literate individuals (Fernandez, 2007; Yin et al., 2007). Yin et al. (2007) suggest that informal cues be used to identify a client with low literacy skills. For example, cues may include the need for assistance in filling out forms; misspelling words or clients who do not understand why they are following particular treatment regimes. While Yin et al. (2007) provide useful guidelines to identify such clients; the literature suggests that it is more important to spend time on providing these clients

with specific tools/strategies to effectively manage their own health, and these need to be developed through research (Moon et al., 1998; Parikh et al., 1996).

The increasing interest in investigating and improving health literacy arose from the staggering costs of healthcare, which are estimated to be billions of dollars in the United States alone (Rao, 2007). Longer and more frequent hospital stays, a lack of comprehension of treatment plans as well as ineffective use of medical prescriptions by clients contribute to these. Policy reports such as Healthy People 2010 (U.S. Department of Health and Human Services, 2000) reveal that low literacy, poor education, poor health and early death are strongly linked not only in the United States but also in the rest of the world. As a culture, the world of poor health literacy is hardly ever considered and poorly understood by healthcare practitioners in general (Weiss & Coyne, 1997). No data on the influence of low literacy on the healthcare costs or success of Speech-Language Pathology treatment plans in South Africa could be located which further adds to the need to explore this topic in the field of Speech-Language Pathology.

### **1.3. Client recall/memory: a background**

An important aspect in providing health information to clients, in addition to issues of health literacy, is that of clients' actual recall/memory of that information and instructions after consultations. Santo et al. (2005) clearly described this concept, linking it to health literacy. They stated that acquired knowledge about health and recall/memory is the retention of medical information, both short- and long-term. Park et al. (1992) affirmed that a combination of comprehension, working memory, long-term and prospective memory is necessary for adherence to clinical recommendations. A client's recall/memory of information and adherence to treatment is affected positively by increased medical knowledge, perceived importance of information and information being expected, welcome and presented in a organised verbal or written way (Isaacman, Purvis, Gyuro, Anderson & Smith, 1992; Ley, 1979).

There are various explanations for clients' tendency to forget clinical information. With reference to the clinician, complex language and the provision of too much and disorganised information can make it difficult for a client to recall information (Fitzner & Fielding, 1994; Flocke & Stange, 2004). With reference to the client; level of education, stress, anxiety and state of health at the time of consultation; increasing age; perceived unimportance and complexity of information; differences in role expectations regarding rights, duties and responsibilities; and clients "switching off" as a result

of feeling overwhelmed by the emotional impact of the information that they receive may affect recall (Ley, 1979; North, Cornbleet, Knowles & Leonard, 1992; Stone, 1979). In addition, clients may forget recommendations for their rehabilitation once they are at home in a more relaxed environment because the advice was given in a stressful clinical environment and there is a mismatch between the two contexts which hampers memory retrieval (Ley, 1979). This could be a problem in Speech-Language Pathology when clients are consulting a SLP in a hospital or clinic as most treatments require clients to follow extensive home programmes (e.g. in fluency or voice therapy). If they do not recall important details and clinical recommendations at home, the success of their treatment would typically be affected.

Ley (1979) addresses the relationship between age and memory skills: counter to expectations of North et al. (1992) and Stone (1979), elderly people may have had more experiences with the healthcare system than younger individuals and may therefore have better recall than their younger counterparts. According to Ley (1979), age and levels of intelligence are not consistently related to better or worse memory of medical information. Kessels (2003) disagrees with the above by stating that the general aging process creates difficulty in encoding, subsequently remembering and eventually recalling medical information. This is especially true when the “new” information contradicts the pre-existing beliefs of an elderly person. In Speech-Language Pathology, many clients that present with dysarthria, neurogenic language, voice or swallowing disorders as well as laryngectomies are elderly. Considering the above, it would seem to be important to address recall/memory of clinical information as well as health literacy skills during consultations with all clients and especially with the elderly if SLPs want to improve compliance and the success of treatment in any population group.

#### **1.4. Research in health literacy and client recall: South Africa and abroad**

##### **Overcoming challenges in health literacy and client recall**

###### ***Health Literacy***

Numerous studies on health literacy have been published in various fields, including nursing, paediatrics, psychology, oncology, HIV/AIDS and pharmaceuticals. Topics range from ways to improve health literacy to issues around client-provider communication (Bellardie & Harris, in

press; Chang & Kelly, 2007; Ciechanowski, Katon, Russo, Walker, 2001; Kreuter et al., 1999; McClement & Hack, 1999; Roberts, 2002; Sanders & Brosco, 2005).

Coulter and Ellins (2007) conducted a systematic review of studies in the literature and electronic databases for evidence on quality interventions for informing clients about healthcare. They identified 129 reviews and reported that improving health literacy had a significant positive effect on clients' knowledge, their experiences, use of health services, their health behaviour/management and health status. Furthermore, they recognised that health education interventions do improve clients' knowledge about health and information recall/memory in both clients with limited literacy and those with good literacy skills (Weiss & Coyne, 1997; Yin et al. 2007).

Researchers like Rao (2007), Margolis (2004), Doak et al., (1998), Back, Arnold, Baile, Tulsy and Fryer-Edwards (2005), Andrulis and Brach (2007), as well as Weiss (2007) have suggested pointers for clinicians to use to improve health literacy and effective client communication. Firstly, they suggested using additional information aides and strategies like showing or drawing diagrams to enhance clients' understanding and recall, or limiting the amount of information given at each visit and constantly repeating it. Secondly, health professionals should always ask clients to demonstrate or repeat what they understand before they leave the consultation. This is also known as the "teach-back" method (Osborne, 2008c) which is based on the principle that effective education of a client requires knowing what they already know, telling them new information and asking them to effectively "teach-back" the information presented to them. Lastly, they suggested that client education and other materials are evaluated and fine-tuned; checking if they are culturally and language appropriate and never targeting them above the eighth-grade literacy level.

Written information by itself may not meet the needs of clients and can exclude certain client groups (e.g. individuals with limited literacy skills and visual skills) (Santo et al., 2005; Valerie & Arthur, 1995). Most healthcare institutions have ready supplies of forms, pamphlets and instruction sheets which are freely distributed. However, it is apparent that much of this literature goes unread even by able readers as they do not have the time and level of interest it takes to access them (Plimpton & Root, 1994). As an alternative, Santo et al. (2005) and Weiss (2007) suggest that more use of audio- and videotapes as well as computer technology should be used.

Yin et al. (2007) caution that there is currently no consensus among health professionals and researchers about which interventions should be incorporated into clinical practice. Furthermore,

Coulter and Ellins (2007) advised that despite evidence of the benefit of innovations to advance health literacy, barriers include lack of awareness, skills and knowledge on the clinicians' part and concerns about time and resource pressures in the clinical setting. The length of follow-up in studies was often rather short, so the long-term effectiveness of several interventions is unknown (Ammenwerth, Brender, Nykänen, et al., 2004). Few studies evaluated the cost effectiveness (and availability), cultural appropriateness and user-friendliness (including sensitivity to resources and skills needed) as well as educational effectiveness and time efficiency of initially setting up or maintaining a strategy. This should be key to any investigation into strategies to improve healthcare because ultimately, one wants to find a solution which can be implemented economically. Yin et al. (2007) concluded that research into the development of effective, appropriate, user-friendly and accessible interventions is vitally important.

### ***Speech-Language Pathology***

Hester and Benitez-McCrary (2006) noted that very little research in health literacy has been conducted in the field of Speech-Language Pathology. To the researcher's knowledge, none of this has been published in South Africa and the relevance of client recall/memory in Speech-Language Pathology has yet to be explored in this context. This is true for both Speech-Language Pathology and Audiology, despite the IOM (2004) identifying speaking and listening as areas in need of improvement in health literacy research and intervention. When asked what professionals of communication sciences and disorders can do to improve health literacy, Moritsugu (2007) replied:

“Health literacy is about communication—to be able to hear the message, speak the message, and understand the message. (SLPs and Audiologists) know how important clear communication is to health and wellbeing. (...) As audiologists and SLPs, you help people across the lifespan to communicate. You help break down barriers in their community. You literally give them their voice and ability to hear. What better group is there to take on this issue of health literacy? Health literacy can save lives, save money, and improve the quality of life for all of us. As a discipline and as individual clinicians, you dignify the lives of those, whom we serve” (p. 17).

That being said, only four related studies could be identified. One study focussed on the effectiveness of additional copy of recommendations during consultations with clients who were managed for a cleft lip and/palate (Paynter, Jordan & Finch, 1990). Another study focused on readability of educational materials for clients with cleft lip and/or palate and their families (Kahn & Pannacker, 2000). SLPs Harris, Fleming and McDougall (2003) focused specifically on the effects

of reader and text variables on understanding of health information in 60 adults (between the ages of 19 and 83) while using the *Test of Functional Health Literacy in Adults* (TOFHLA). A fourth study by Shadden and Raiford (1984) examined the factors that had an effect on the utilisation of Speech-Language Pathology services by elderly individuals.

Paynter et al. (1990), found that 92% of respondents who attended a clinic for cleft lip and/palate management felt that receiving an additional written copy of clinical recommendations at the time of consultation was helpful. In a subsequent study Paynter, Wilson and Jordan (1993) used the former findings to make changes in order to provide better service and improve patient compliance and the efficiency of their clinic. The subsequent mean rate of compliance was 82%, compared to the previous 64%, and only 3.3% of the clients included in this study were non-compliant. This indicates the need for written materials to be offered in addition to the verbal information and advice that is provided during consultations. However, Kahn and Pannbacker (2000) found that the comprehension of these materials depends on the (a) level of readability, (b) clients' literacy skills, (c) their level of interest in the material, (d) their cognitive ability, (e) relevance of the material to the client or their family and (f) previous exposure to knowledge about the information that is outlined (Kahn & Pannbacker, 2000) which makes this strategy less ideal when these variables are affected.

SLPs Harris, Fleming and McDougall (2003) found that there was no correlation between prior knowledge and functional literacy, and health literacy comprehension which agrees to some extent with Glassman's (2007) statement that individuals with high functional literacy do not necessarily have high health literacy skills and vice versa. Findings from this study and the study by Kahn and Pannbacker (2000) showed that the investigated materials in Speech-Language Pathology exceeded the reading level of many clients and their families. This is an alarming finding considering the fact that SLPs rely extensively on providing written information to clients (Harris, et al., 2003; Kahn & Pannbacker, 2000). Finally, results of the study by Shadden and Raiford (1984) showed that limited health literacy was a barrier to clients receiving adequate speech and hearing services. All of this demonstrates the need to raise awareness and implement strategies to enable clients with all levels of health and general literacy skills to understand services and adhere to recommendations.

One study that was conducted by a South African SLP did not focus specifically on health literacy but considered one aspect of it (i.e. dynamics of health information exchange), while exploring caregivers', counsellors' and medical doctors' experiences regarding communication in HIV/AIDS

health care in a tertiary health care setting in Cape Town. Cilliers (2005) aimed to describe and explain the meaning and essence of the experiences of communication in a paediatric outpatient HIV/AIDS clinic. In addition to variables that effect health literacy (as was discussed under section 1.2.), she found that caregivers' experiences of communication of health information and their behaviour and communication in HIV clinics were largely shaped by health professionals' empathy, disease complexity, clinic organisation (availability of counsellors, interpreters, resources and time) and functioning relationships between medical doctors, counsellors and interpreters. Even though she did not focus on health literacy and its role in the field of Speech-Language Pathology, the overall point made here is that health information exchange is complex and dependant on various personal, inter-personal and contextual variables which need to be understood and improved on so that the effectiveness of consultations and post-consultation management can be maximised.

Regardless of the guidelines that were provided to improve health literacy, the issue of client recall/memory of healthcare instructions and its effects on the actual outcomes of management will still be present.

### ***Client recall/memory***

In his review of experimental evidence regarding the obstacles to memory for medical information, Kessels (2003) states that recall/memory of medical information and recommendations are prerequisites for adherence to treatment. This is an important point to consider in light of the widely held assumption that only good health literacy skills are responsible for an increase in adherence to medical recommendations. However, some clients find little logic in what happens during and after consultations. This is because they face the stress of a medical crisis, often without the presence of a significant other person or while in great pain, confusion or depression (Rao, 2007). Fourty to eighty percent of medical information presented by health professionals is forgotten immediately and nearly half of the information that is actually remembered is incorrect (Anderson, Dodman, Kopelman & Fleming, 1979 as cited in Kessels, 2003). In a general practice setting, seven to 47 % of clients do not recall or understand their diagnosis after a consultation (Ong, de Haes, Hoos & Lammes, 1995).

In their study on discrepancies between clients' and professionals' recall and perception of an outpatient consultation, Parkin and Skinner (2003) found that there was significant disagreement between professionals' and clients' recollection and perceptions of the content of their consultations.

This implies that even when health professionals assume that their clients would recall the health information that was provided, this might not necessarily be the case. Health professionals often underestimate many factors (e.g. emotional stress, time pressures, hurried clinics) which work against the likelihood of clients remembering what health professionals tell them (Margolis, 2004). It is apparent that the Speech-Language Pathology and Audiology profession and the literature on communication professions pays minimal attention to issues around clients' memory of critical health information (Margolis, 2004), even though retention of vast amounts of information (i.e. diagnosis and recommendations) are critical to treatment outcomes.

Kessels (2003) and Ley (1979) suggested guidelines to enhance client memory. For example, information should be categorised into explanations of systems, tests, the prognosis and lastly the results. At the end of each category, the client should be asked if they understood what was described before moving on to the next category. Clients may still forget if professionals do not provide additional materials to ensure that when they leave the clinical setting, the information they have is clear, accurate, complete and available for review and discussion with other professionals or family members (Kessels, 2003). The amount of time spent explaining and discussing important health information and recommendations also correlates with the amount of information that is recalled by the clients (Flocke & Stange, 2004). It would seem that this trade-off between (a) the time initially spent on ensuring the client understands and will remember clinical information, and (b) better recall and subsequent adherence to recommendations is an important feature to consider in therapy.

Stone (1979) and Hoffman and McKenna (2006) added three more aspects to the responsibilities of professionals. Firstly, a professional needs to fully explore and attain insight into each particular client's situation, not only with regards to their presenting problems but also possible barriers to adherence which might exist (e.g. anxiety or other overriding individual concerns). Secondly, health professionals need to acknowledge clients' individual learning styles. Some may learn better through visual cues, others through auditory cues and some prefer to learn through the use of kinaesthetic or tactile cues. In practical terms, this might translate to providing information in a range of different materials (e.g. written or audio-visual) (Hoffman & McKenna, 2006). Lastly, people have varying ways of thinking and solving problems (Hoffman & McKenna, 2006) and it is important not to assume that all clients will respond to the same materials or methods in management. Coulter and Ellins (2007) as well as Kessels (2003) emphasised that well designed written health information (e.g. leaflets), the use of audiovisual aids, pictorial illustrations, as well as

group or individualised health information sessions to improve understanding and recall can be valuable and are most effective if they are used as a supplement to professional consultation and advice. Ley (1982) pulled all the above factors together and affirmed that clients who (a) are satisfied with the medical care they received, (b) understand (through adequate health literacy skills) and (c) recall the medical advice which was provided to them, are more likely to comply with clinical recommendations.

### **1.5. Further issues around information exchange and client compliance specific to the South African context**

Having discussed challenges of health literacy and recall/memory in clients, it is viewed to be important to investigate any further issues or contributing factors to non-compliance especially in the South African context. The first two sections examine factors that are beyond the scope of this study but their reference here is important because they are perceived to have an additional role to play when it comes to the success of information exchange in the clinical setting. The third section investigates reasons above and beyond health literacy and client recall/memory that bring about clients' non-compliance with treatment regimes and the fourth section provides resolutions to some of the obstacles that are outlined.

#### ***Professionals' individual characteristics***

The first issue concerns the differences in each professional's level of experience, fundamental beliefs and principles that influence the way that they provide therapy (Bastable, 2006). Beside assessments, counselling and therapy, the way in which SLPs manage health literacy and recall/memory in clients could be highly individualised. For example, they might have different ways of approaching the provision of information to clients and their families (Tooth & Refshauge, 2006). Some might rely mostly on verbal feedback while others provide extensive written materials. Furthermore, people living in South Africa are culturally diverse (Kagee, 2004) and cultural differences in health professionals result in varied health beliefs (Katz & Scarpati, 1995). Depending on how reflective the professional is; the appropriateness of health information and effective communication with clients of varying cultural backgrounds will be impacted (Katz & Scarpati, 1995).

#### ***Culture, language and literacy***

The differences in language and literacy in South African clients partly influence the success of healthcare, while the range of South African clients' cultural backgrounds also come to play an important role in the utilisation of healthcare (Kagee, 2004). Knowledge of clients' cultural backgrounds is a vital characteristic for any health professional working specifically in the South African context. Culture is a framework that a person uses in viewing health and the need for care and it is often influenced by geographical location, ethnic backgrounds and personal attributes (Bunning, 2004). For example culturally diverse families may prefer traditional health and healing practices over westernised therapy processes (Zhang & Bennet, 2001). If a client chooses not to adhere to treatment prescribed by an SLP because of their cultural beliefs, they might be perceived as noncompliant. For example, SLPs may advise parents to stimulate their children's speech and language from an early age, but in some cultures, it is not customary to speak with children directly until they reach a certain age (Marfo, 1993).

What may also increase the perception of non-compliance, especially in the South African client population, is that there is a culturally determined tendency to accept information noninteractively (without objections or questioning), even when the information may not be entirely understood. This is viewed to be an African characteristic, and it may contribute to a general lack of acquired knowledge in healthcare (Marfo, 1993). This characteristic may be explained by tactics of saving face, different child-rearing practices, unequal power relations between clients and professionals, short durations of consultations and a hesitancy to be open with authoritarian figures like medical doctors (Cilliers, 2005; Marfo, 1993). Clients might prefer a rather "paternalistic style" of client-provider relationships in consultations which means that the health professional is primarily made responsible for the treatment and wellbeing of the client (Beisecker & Beisecker, 1993).

However, Ewart and Till (1998) reported that clients' passivity during consultations in actual fact reflected their acknowledgement of the medical expertise and the authority of the health professional. Clients' choice of a more passive role in consultations seems to be reasonable given that they do not have the medical resources or knowledge to reach treatment decisions nor the authority to implement them (Ewart & Till, 1998). Regardless of how this characteristic of passivity or noninteractivity is explained, it raises the prospect of reducing clients' roles in decision-making as well as their success in managing their own health (Marfo, 1993).

South Africa is a linguistically diverse country where over 11 *official* languages are spoken (Big Media Publishers, 2007). Nevertheless, South African public healthcare is still characterised by a

large language divide (Marks, 1994 as cited in Jewkes, Abrahams & Mvo, 1998). isiZulu and isiXhosa have the highest number of first language speakers in South Africa but the majority of South African health professionals are proficient only in English and/or Afrikaans (Drennan & Swartz, 2002; Statistics South Africa, 2001). Even though countless South Africans can speak several languages, their literacy skills in all of these may be limited (Underwood, 2002). Many older generations (of people who speak African languages), who were educated under the apartheid system, cannot read or write in their native language which means that even when written materials in Speech-Language Pathology are translated, they are of no assistance to them. Additionally, their literacy skills in English and Afrikaans, which were the only languages allowed for education during apartheid, are not sufficient because of inequities in the quality of education that was provided to them at the time of the regime (Kagee, 2004; Samuel, 1990). Thus, most materials written in these languages are also not appropriate and therefore another strategy needs to be implemented. When cross-cultural communication is improved, it may lead to increased client involvement in care, their adherence to treatment regimes, a higher quality of care, and better overall health outcomes (Cooper-Patrick, Gallo, Gonzales, et al., 1999) in addition to quality strategies to improve health literacy and client recall.

***Variables to client compliance (unrelated to health literacy or recall/memory)***

McDonald et al. (2002, p. 2868) defined compliance as “the extent to which a client’s behaviour (e.g. following a diet or attending clinics) coincides with medical or health advice”. There are various types of non-compliance which range from non-participation in routine screenings or other health checkups, to not showing up for appointments, failing to follow clinical instructions and recommendations and stopping treatments too soon (Vermeire, Hearnshaw, Van Royen & Denekens, 2001). Ley (1982) and Paynter et al. (1990) in their articles on client satisfaction, compliance as well as communication and client compliance with cleft palate team regimes identified some variables that are related to clients’ non-compliance. These ranged from the effectiveness and cost as well as the satisfaction with the treatment regimen, to the lack of follow-up by health professionals.

Bunning (2004) made an additional and interesting suggestion regarding obstacles that need to be considered when wanting to activate behavioural change in a client who is managed by a SLP. She emphasised that fear of failure or of “looking stupid” (Bunning, 2004, p. 89) and being insecure may make the individual (and significant others) disinclined to try out their skills in pursuit of managing their own health. Furthermore, knowing what a child or partner was like before a traumatic brain

injury or a stroke, can make it difficult for significant others to accept the “new” person which in turn makes it more difficult for the client to be enthusiastic towards complying with Speech-Language Pathology treatment regimes (Bunning, 2004).

Long waiting times at clinics (a common reality in government hospitals/clinics in South Africa) or lengthy time lapses between appointments (McDonald et al., 2002), which sometimes is the reality in Speech-Language Pathology treatment programmes for example when managing voice and laryngectomies, also affect compliance. Furthermore, clients typically define adherence in terms of their view of good health and they only seek treatment approaches that are (in their view) manageable, tolerable and effective (Kagee, 2004). For example voice therapy requires structured treatment sessions as well as home-programmes to be completed outside the therapy session. However, it is frequently characterised by problems of resistance to change and lack of post-consultation follow-through (Portone, Johns & Hapner, 2006). For instance, a smoker will find it difficult to gradually stop smoking 30 cigarettes a day so that he/she can preserve his/her voice. Thus, low adherence to treatment regimes may be intentional or unintentional (Kagee, 2004). Many clients also only consider medication, rather than behavioural regimes to be treatments (Kagee, 2004). This is another interesting and important factor to consider especially in light of the nature of Speech-Language Pathology interventions which do not typically make use of medications but prescribe behavioural changes and recommend adherence to therapeutic strategies.

Poverty is another variable that affects the compliance of formerly oppressed communities the most (Kagee, 2004). The way that poverty reduces self-efficacy may be truly unique to clients living in historically disadvantaged South African communities (Kagee, 2004). The demands and stresses of daily survival, work and family life may contribute to the lack of acknowledgement of the importance of complying with treatment regimes (Kagee, 2004). For example, money to pay for travel and Speech-Language Pathology consultations may need to be prioritised for more urgent needs and a person who has only an open fire for cooking and heating would be less able to adhere to advice regarding avoidance of smoke to preserve his/her voice.

### ***Resolutions***

Resolutions that contribute to adherence to treatment regimes are; a high level of social support and self-efficacy, a strong belief in the usefulness of medication or therapy as well as an open and supportive relationship with the health professional (Ciechanowski et al., 2001; Kagee, 2004; Roberts 2002). Another factor related to compliance and thought to be vital for the improvement of clients' health status is a client's motivation: a characteristic without which any strategy,

recommendation or treatment regimen will be less successful (Richards & Sayward, 2006). Information needs to be relevant and clients' confidence in their own abilities and self-efficacy needs to be upheld. Health professionals need to acknowledge that clients need to be attentive and confident and fully comprehend what is being discussed during consultations for them to stay motivated and be able to concentrate on managing their own health (Kubeck, 2002; Rosenstock, 2005). Wilson and Cleary's (1995) model further integrates variables that have a direct/indirect impact on clients' quality of life and adherence to treatment regimes. They classified the relationships among measures of (a) characteristics of the client (e.g. personality, motivation or general health perception), (b) characteristics of the environment (e.g. social, economic and psychological supports), and (c) a client's symptom and functional status as well as biological/physiological variables. Biological or physiological variables (function of body) impact a client's symptom status (perception of abnormal physical, cognitive or emotional state) which in turn impacts their functional status (physical, social and psychological functioning). All the while, the characteristics of the client and the environment affect a client's symptom and functional status while together they all contribute to a client's overall quality of life and adherence to treatment. Wilson and Cleary (1995) thus hoped that when these variables can be understood and acknowledged, it would facilitate the design of effective clinical interventions to improve client compliance.

In the presence of limited financial resources in the South African health sector, it is of great importance that issues around client adherence are fully understood and compliance be improved in order to enhance the effectiveness of treatments. Non-compliance with treatment is likely to have far-reaching health, economic and social implications in the South African context where financial resources are scarce, public funds are inadequately divided and there is a low ratio of medical staff to clients (Kagee, 2004). Without conscious and planned consideration of the above variables, the actual therapy process is incomplete and subsequent therapy outcomes will remain unknown (Bunning, 2004). With the increase of clients having to take charge of their own health management as a result of financial constraints and (contact) time restrictions with health professionals, there is a dire need for better understanding and management of non-adherence so that compliance can be improved (McDonald et al., 2002). This would typically also alleviate pressures on healthcare resources.

The role of professionals' individual characteristics, clients' language, literacy and culture, variables in compliance in addition to health literacy and recall are elements that are very relevant to the field

of Speech-Language Pathology and this study in that they inevitably play a role in the success of consultations and therapy processes. Thus, the above-mentioned concepts need to be considered and addressed collectively (Kagee, 2004) because client non-compliance is costly and may contribute to considerable wastage of resources (e.g. consultations, medication and transport). It is harmful to clients' health as it may have severe implications for the control of symptoms (e.g. aspiration pneumonia secondary to swallowing disorders), time taken for recovery and quality of life (Kagee, 2004).

## **1.6. Practical solutions for improving health literacy, client recall/memory and compliance in general**

McDonald et al. (2002) and Kagee (2004) identified various studies that tested different interventions (alone and in combination) to improve compliance. Almost all the interventions that were effective in long-term healthcare were complex. They included combinations of aspects such as more convenient healthcare, multimodal instructions to clients (verbal instructions together with written materials), effective provision of information, ongoing counselling, reminders (e.g. through telephonic follow-up) encouraging self-monitoring and continuous reinforcement of recommendations (McDonald et al., 2002). The complexity of the problem of client non-adherence suggests that no single solution is likely to be helpful and strategies are actually more functional when combined (Kagee, 2004; Vermeire et al., 2001).

### ***Introduction to health informatics***

In South Africa, medical education and healthcare is characterised by a rising interest in technology (Hugo & Skibbe, 1991). Reviewed research into consumer health informatics (Eysenbach, 2000; Heathfield, Pitty & Hanka, 1998), a field of medical health informatics, has gained momentum in the past few years (Eysenbach, 2000). It focuses on (a) clients' information needs and use, (b) evaluating effective methods/technologies to assist clients in obtaining and using health information, and (c) the effects of these methods on public health, client-professional relationships and the society as a whole (Eysenbach, 2000). The driving factors in this movement are the emergence of evidence-based practice, the need for improving clients' abilities to practice self-care and make informed choices and the growing awareness that relationships and information exchange between health professionals and the general population need to be improved as a result of an effort to cut healthcare costs (Coulter, 1999; Eysenbach, 2000). Although these positive developments

potentially improve the provision of appropriate health management, those who do not have access to certain technologies are excluded from this vital opportunity. The cycle of low health literacy and educational levels, poor income and health as well as the inaccessibility of information technology can only be broken if research is directed towards bringing information technology to those who are underserved (Eysenbach, 2000).

The following section explores different materials and strategies which were proposed and have been used widely to assist clients with limited health literacy and general literacy skills to manage their own health. This section will be concluded with a presentation of suggestions gathered through personal interviews with experts of information technology. Some of the materials or strategies are high tech, which means that highly advanced and specialised technology is used (e.g. digital video cameras), and some of these strategies are low tech which means less advanced technology (e.g. illustrations) is involved (Compact Oxford Dictionary, 2008).

### ***Pictographs***

In many non-literate societies, pictographs have been used to assist individuals with limited literacy skills to remember spoken instructions. They attract attention and in general, clients' understanding and memory of clinical information is better when they actually *see* the message in pictorial form. (Houts, Witmer, Egeth, Loscalzo & Zabora, 2001; Mansoor & Dowse, 2003). Even though pictogram-enhanced materials improve the comprehension of medical information by 80% (as opposed to 14% when only spoken instructions are provided) (Margolis, 2004), it is important to understand that the recognition and understanding of visual messages requires visual literacy, which must be acquired separately from reading and written skills. Without visual literacy the message encoded on a poster, leaflet or television programme is lost. Visual literacy is acquired through experiencing and learning how to create and use visual symbols for communication (Hugo & Skibbe, 1991). Pictographs may also not always be practical in the management of neurogenic language disorders, dysphagia, voice disorders (including laryngectomies) or cleft lip and/or palate because of the nature of management in these areas of practice, which are typically multi-faceted and often too abstract to readily depict (e.g. vocal exercises or how to take care of a child with feeding difficulties). Furthermore, additional time and human resource is needed when the meaning of more complex pictographs has to be explained to clients initially, so that it can be understood and recalled at a later stage (Houts et al., 2001).

### *Video-/Audio-recordings*

The provision of video or audio-recordings (in the form of cassettes or CDs) has been suggested to improve health literacy and client recall/memory (Knox, Butow, Devine & Tattersall, 2002; Rao, 2007). Santo et al. (2005) investigated the use of audiotapes as a tool to give clients of diverse backgrounds for review of clinical information and recommendations at home. They reviewed 35 articles on this topic and they found that studies differed when it came to the improvement of client knowledge and recall when tape-recordings of clinical information were provided. However, they did identify several studies which showed that tape recordings of consultations can increase knowledge of clinical information. They also identified studies which indicated a significant increase in behavioural change and self-care in clients when audio-recordings of their consultations were provided. For example, Tattersal et al. (1994) found that clients particularly preferred an audiotape with information provided during consultations to an individualised letter outlining basic points, which suggests that there are pieces of information and reassurance on a tape that may be lacking in a letter. Clients also reported that listening to a voice was more reassuring, personal and human than a letter. Medical doctors thought that clients would benefit from a tape recording of the consultation as it would provide the advantage of additional information and comfort as well as the ability to share it with family and friends and the inclusion of both parties as participants in the consultation. However, some professionals thought that a letter would be easier to file, store, and copy and it was more appropriate for speedy review and reference (Stockler, Butow & Tattersal, 1993).

Additional advantages of audio-recordings are that the client is able to listen to a personalised recording and review information as often as they want or need. They can share the recording with family and thereby decrease misunderstandings and forgotten details. This is especially important when two or more individuals share care-giving of a client. Audio-recorded information could potentially decrease consultation time and resources (thereby reducing healthcare costs) because clients are enabled to review and understand information which would typically improve their rate of recovery. This strategy is relatively inexpensive, and it has the advantage of the spoken word, which has greater power to hold attention than the printed word (Santo et al., 2005). Disadvantages of audio-recordings are that clients need to have access to a cassette/CD-player, and recording consultations might inhibit open discussions.

Doak, Doak and Meade (1996) evaluated multimedia for client education and they drew attention to a device that can serve audiotaping as well as audiovisual needs. The Compact Disc-Read Only

Memory (CD-ROM) has a large storage capacity. It could be programmed in any native language and used for educational purposes about disorders and related treatments once clients are in their home environments, allowing access to sound, pictorial and written health information. Multimedia have the potential to provide clients with the appropriate conditions for learning and their responses to the information presented could provide health professionals with evidence that clients understood the recommendations given to them (Doak, Doak & Meade, 1996). The positive response to multimedia strategies are constantly increasing with people from all walks of life being exposed to the latest media such as DVDs, CDs, video gaming and the internet (Hui Kyong & Keenan, 2006). While considering the above, it is clear that these media should be used more actively in healthcare.

### ***Short Message Service (SMS)***

Another relevant technological invention is the mobile phone and its SMS feature. Mobile phones are cheap and easy to operate. It is estimated that over 50 % of the people living in the Cape Peninsula have access to mobile phones. Over 70 % of South Africans already make use of them (Internet World Stats, 2007) and South Africa's cellular networks cover 90 % of the country, outstripping land lines in most rural areas (Lindow, 2004). This feature is already used by various organisations such as the Sizophila Project, an AIDS treatment programme in Gugulethu (Cape Town) (Lindow, 2004). Through the use of menus on their mobile phones, therapeutic counsellors can monitor and update adherence to treatment regimes and provide detailed social information in clients' digital files at a clinic, while visiting clients (Lindow, 2004).

Another study conducted by the International Institute for Communication and Development (IICD) in Cape Town, used SMS reminders to alert clients with tuberculosis (TB) to take their medication. The outcomes of this project proved to be highly successful resulting in only one treatment failure of the 138 clients involved (IICD, 2006). Osborne (2008a) suggested that the SMS technology be used for reminders especially with young people as they typically enjoy sending frequent text messages to each other. For example, a child that needs to implement certain behaviours to manage his/her voice disorder or fluency disorder, might benefit from an occasional reminder of the main points of therapy. They also might benefit from being in SMS contact with the SLP when problems arise. SMSs could also be of assistance to adults with voice disorders, laryngectomies or dysarthria who have questions or need reminders on certain aspects of therapy.

Reading and compiling SMSs might be difficult for people with low literacy. However, Lurie and Parker (2007) proposed that schools equip students to become an “intergenerational” resource to their parents and grandparents (e.g. helping them with reading or sending text messages etc.). If health professionals make use of this strategy, they need to ensure that clients have access to a caregiver or other person who can help them if necessary.

### ***Telephonic contact/follow-up***

Osborne (2008b) evaluated the uses of telephonic communication for providing and reinforcing clinical information, ultimately to improve health literacy and recall of clinical information. Firstly, she suggested that clients and their families should be encouraged to call the health professional in times of need. By knowing that they can get into contact with their health professional, their anxieties may be eased considerably, even though it has been found that clients and their families seldom take advantage of this offer. Secondly, Osborne (2008b) suggested that health professionals make telephone calls to clients after clinical visits so that they can answer a client’s questions and remind them of important clinical recommendations. It is especially helpful to do this after clients have had a chance to review and process information at home, away from the stressful clinical environment (Osborne, 2008b). This particularly applies in Speech-Language Pathology where treatments are complex and new problems which might occur as clients recover, need to be addressed promptly. It might take a while for clients to realise their responsibility in making contact with their SLP and Osborne (2008d) suggested that clients do become more self-efficient after a few “practice-sessions” with the help of their health professional. The only obstacle is that telephonic contact is not always cost-effective (Minges, 1999).

### ***Personalised clinical information***

Health advice and clinical information that is personalised and tailored to the unique needs, interests, and concerns of the individual has been shown to be more effective in assisting clients adhere to recommendations than general information materials (Kreuter et al., 1999). Individuals who receive personalised information materials are significantly more enthusiastic about their treatment compared to individuals who received non-tailored materials (Kreuter et al., 1999). Reasons for this could be that (a) unnecessary information is eliminated and information is more relevant to the individual, and (b) more attention is paid to information that is perceived to be relevant thus it will lead to more thoughtful consideration of important recommendations (Kreuter et

al., 1999). All information aids have some positive and some negative implications and while most of them could be effectively used in Speech-Language Pathology, it is realised that not all of them are appropriate for people with low literacy skills, financial resources and complex disorders. It is understood that there is a need for research on information aids to move towards specifically addressing the needs of these specific clients, who consult SLPs (Santo et al., 2005).

### ***Experts in information technology***

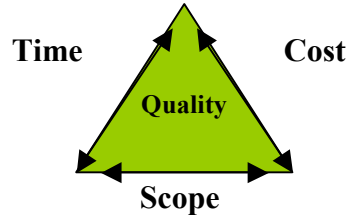
In an effort to find out more about information technologies/systems and other media, four individual interviews were held with four experts who had experience and expertise in information systems, industrial and electronic instrumentation, information technology management and alternative and augmentative communication systems. These experts had considerable knowledge and experience about information technology from a developmental and research perspective. The researcher proposed the research problem and in turn they were asked about strategies that SLPs could use to improve health literacy and recall/memory of clinical information in clients (see Appendix A for interview schedule). These experts continued to present solutions from within their field. Suggestions that were put forward were low cost SMSing through the internet, audio-visual materials to be viewed on DVD or as video-clips on mobile phones, voice messages and reminder functions on mobile phones as well as reminders for clients based on the idea of a call centre. Details of their suggestions were summarised and tabulated in Table 1 (see Appendix B).

### ***Advantages and Disadvantages***

In addition to the strategies that were outlined in the literature review, Table 1 shows a range of other technical possibilities. There are however some disadvantages to each of these strategies. Not all mobile phones (especially older and cheaper ones) have video or reminder features (Elite Mobile, 2006). Furthermore, many of these strategies will require SLPs to become skilled in the use of some of the multimedia technology. Costs and other material logistics would also need to be addressed. It is important to remember that clients have different learning styles (Hoffman & McKenna, 2006). Thus, SLPs may prefer access to various strategies depending on the needs of the client. They might also have individual preferences over certain strategies/technologies depending on how easily these could be integrated into their practice. Therefore, finding a single strategy to serve as a universal tool for information exchange between clients and health professionals would be a challenge.

### ***Relevance of concept of project management***

One of the experts highlighted the concept of the “triple constraints” and how it could be adapted and applied to finding appropriate strategies. The “Triple Constraints Model”, also known as the project management triangle (DeCarlo, 2004), describes the balance between a project’s or strategy’s scope, its cost, schedule/time to complete it and its quality.



*Figure 1. The Triple Constraints (DeCarlo, 2004; Pearlson & Saunders, 2004).*

Any change in any one of the sides of the triangle affects one or both of the other sides. Increased scope typically means increased time and increased cost, while a tight time constraint could result in increased costs and reduced scope. Similarly, a tight budget could mean increased time and reduced scope (DeCarlo, 2004; Dobson, 2003; Pearlson & Saunders, 2004). According to Dobson (2003), a successful balance of time, scope and cost results in the creation of a high-quality project (a project which meets the needs and expectations of the individuals that use it).

During discussions with the experts of information technology, it was established that any strategy that is used or invented needs to be cost-effective, culturally appropriate and user-friendly. If one captures the basic idea behind the Triple Constraints Model and applies it to these variables, a similar dependant relationship can be identified. Decreased cost could result in decreased investment into making strategies user-friendly and culturally appropriate. Furthermore, decreased user-friendliness would call for less cultural appropriateness and reluctance to purchase. Similarly, decreased cultural appropriateness would result in a strategy being viewed as less user-friendly and there would be reluctance to purchase. Figure two illustrates this adapted concept.



*Figure 2. Application of Triple Constraints Model in this context.*

When decisions are made on implementing a certain system/strategy for the management of client health literacy and recall/memory, this dependant relationship between constraints needs to be revised and considered at all times.

### **1.7. Rationale for focus on voice (including laryngectomy), dysphagia and cleft lip and/or palate management**

After having considered all aspects of a SLP's scope of practice, it was decided to focus on clients with: voice disorders (including laryngectomies), dysphagia or cleft lip and/or palate. This is because clients' understanding and recall of information in these disorders is most critical to compliance with treatment (Fagan, Lentin, Oyarzabal, Isaacs & Sellars, 2002; Low et al., 2001; Mashima, Birkmire-Peters, Syms, et al., 2003; Sataloff, 2006).

#### **Voice disorders (including laryngectomies)**

Symptoms of these disorders range from hoarseness, vocal fatigue, and absence of the voice to strained and strangled voice (Schwartz, 2004). Voice disorders in adults can be caused by neurological disorders such as Parkinson's disease, vocal abuse and misuse, exposure to toxins and pollution, trauma to the area of the larynx (voice box), cancer and hormonal changes (Colton & Casper, 1996; Sataloff, 2006; Schwartz, 2004). Voice disorders in children can be caused by vocally abusive behaviours such as excessive use of loud voice, asthma or allergies, smoky environments or gastro-oesophageal reflux disease (GORD) (Hunter & Slater, 2003).

In the greater Cape Town area, 19 % of the 3,239 million reside in informal dwellings under poor conditions (City of Cape Town, 2008). They live near highways and cook over open fires which expose them to pollution. Twenty-five percent of the workforce in Cape Town works in petroleum refineries, chemical and plastic/rubber factories where they have to vocally overcome noise and they are exposed to dangerous toxins on a daily basis (City of Cape Town, 2008). The fact that 15 % of people in Cape Town over the age of 14 are illiterate (City of Cape Town, 2008) points towards the need for individuals from this population specifically to be equipped with strategies for achieving better health literacy and adherence to recommendations so that they can avoid surgery or abusing/misusing their voice (Sataloff, 2006).

According to Engelbrecht et al. (2006), there are many clients in South Africa who typically present with *advanced* head and neck cancer among the large number of clients coming from rural areas where awareness of different health risks and the presence of resources are typically low. The client will experience a variety of consequences as a result of total laryngectomy. The most significant are the loss of natural voice and glottic pressure as a result of removal of the larynx which makes coughing, abdominal press and the lifting of heavy objects no longer possible (Deverell, Vorobiof & Ross, 2004). In the long term, the psycho-social consequences of having had a laryngectomy are often even more devastating. These clients experience shock, anxiety and depression (a grief reaction to loss of voice, smell, taste and ability to work and socialise as before their surgery). If not managed appropriately, the client's self worth, family relationships, ability to socialise and employment may be adversely affected (Deverell et al., 2004). Furthermore, Fagan et al. (2002) suggested that there was a significant association between illiteracy, quality of housing, low insight, dexterity and eventual speech failure in people with laryngectomies at later follow-up appointments. It is viewed to be important for SLPs to find ways for improving health literacy as well as recall/memory in clients with voice disorders and laryngectomies as they need extensive support, reassurance, a chance to review information and ask questions.

### **Dysphagia (feeding and swallowing disorders)**

Dysphagia is defined as the “difficulty of moving food from the mouth to the stomach, including all behavioural, sensory, and preliminary motor acts in preparation for the swallow” (Logemann, 1998, pg. 1). Dysphagia has potentially life-threatening health implications for infants, children and adults (Chadwick, JolliVe & Goldbart, 2002). In adults, swallowing disorders typically result from cerebrovascular accidents (CVAs), traumatic brain injuries, trauma to the swallowing mechanism, cancer or progressive neurological disorders/degenerative diseases (Cherney, 1994). In infants and children, swallowing disorders typically result from complications during the birth process, prematurity of birth, cerebral palsy (CP) and traumatic brain injuries (Arvedson & Brodsky, 2002; Cherney, 1994). Health risks include poor nutrition, dehydration, loss of oxygen and aspiration, which can also lead to respiratory tract infections and the need for surgery (Cherney, 1994; Low et al., 2001).

Recommendations and management include dietary alterations, instructions on swallowing safely, postural alterations and alternative means of feeding (Arvedson & Brodsky, 2002; Low et al., 2001). Non-compliance is a risk factor for the development of serious chest infections, malnutrition,

dehydration and weight loss (Low et al., 2001). A study by Leiter and Windsor (1996) showed that SLPs significantly overestimated the level of compliance, understanding and recall in a number of clients carrying out swallow instructions during a meal. In addition, there was a correlation between compliance and the clients' initial understanding of instructions. Thus, there is a definite need for an investigation into ways in which SLPs can improve clients' compliance with recommendations in dysphagia management regimes (Low et al., 2001).

### **Cleft lip and / or palate**

A cleft lip or palate is resultant of the failure of parts of the oral cavity (lip or palate) to merge in the first trimester of prenatal development (Kummer, 2001; Ross & Deverell, 2004a). Most clefts result from a combination of genetics and environmental factors and they may also co-occur with certain syndromes like Treacher Collins Syndrome (Kummer, 2001). Associated problems may include feeding difficulties and hindrances of speech or language development (though not permanent) (Kummer, 2001). The treatment regimen prescribed by a cleft palate team requires prompt and continued compliance in order for management objectives to be met (Paynter et al., 1990). It is important that caregivers follow recommendations and instructions to (a) use special feeding techniques so that their infants can gain weight and (b) be good speech and language stimulators. It is also important that they attend appointments consistently, as the impact and complications of the cleft can become greater with age (Kummer, 2001; Louw et al., 2006).

The written materials that offer this information for review are often handed out together with verbal instructions. Bellardie and Harris (in press) found that overall the English Cleft Lip and Palate Parent Information Leaflet (CLP PIL) currently used at the Cleft Plate Clinic at the Red Cross Children's Hospital in Cape Town, was a useful tool to improve parents' basic understanding of treatments that are available to children with cleft lip and/or palate. They also found that parents expressed a desire and need for PILs at the time of the birth of their child. Even though this is encouraging information it should be noted that Bellardie and Harris's study was not conducted with the isiXhosa and Afrikaans leaflets which means that the results cannot be generalised. Furthermore, individuals who have insufficient English skills and low health and general literacy skills (Kagee, 2004), are not able to clearly understand and make use of these materials (Louw et al., 2006) which supports the need to investigate other avenues or strategies for information review or exchange between health professionals and these particular client populations.

When considering these and multiple other variables mentioned in former sections, it is realised that an investigation is needed to design a strategy that will provide clients (with any of the above disorders) with a chance to review information in order to understand and be able to recall important details to treatment advice. They also need to have a chance to be in contact with their SLP and get feedback when they have questions or experience difficulties in treatment. This is most important because (as was shown in section 1.7.), mismanagement in the selected disorders could result in potentially severe consequences. Health professionals and other stakeholders in society need to commit to being innovative and empower clients to access and use health information through culturally-appropriate, cost-effective and user-friendly strategies (Parker, Ratzan & Lurie, 2003). Health literacy is not only about ensuring that clients can read and comprehend health information, it is also about empowerment. To achieve better health literacy in any population is fundamental to tackling health inequalities and improving the health of disadvantaged communities (Coulter & Ellins, 2007). From an ethical point of view, SLPs might be seen to run the risk of overlooking the principles of non-maleficence and beneficence, if the profession does not invest in means to maximise health literacy and client recall/memory of clinical information in “high-risk”<sup>4</sup> populations. It becomes the onus of professionals not to blame the client for not adhering to or misunderstanding recommendations, but rather to develop appropriate methods for improving information exchange, understanding and recall/memory of clinical information.

The issues covered in the above literature review gave rise to the research question: (a) what are the issues in health literacy and information recall/memory of clients receiving Speech-Language Pathology treatment in public hospitals/community rehabilitation clinics in Cape Town, and (b) how can health literacy and client recall/memory of clinical information be maximised in clients with dysphagia, voice disorders (including laryngectomies and cleft lip and/or palate?

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<sup>4</sup> The term ‘high risk’ in this case is meant to describe groups of individuals who are negatively affected by one or more of the many variables that influence health literacy, client recall and general compliance with treatment.

## **Chapter 2: Methodology**

### **2.1. Aims and Objectives**

The aim of this study was to;

- a) explore health literacy and information recall/memory of clients receiving Speech-Language Pathology treatment in public hospitals/community rehabilitation clinics in Cape Town, and
- b) to explore ways of maximising health literacy and client recall/memory of clinical information in this population with specific focus on clients with dysphagia, voice disorders (including laryngectomies) and cleft lip and/or palate management.

The objectives of this study were to:

- 1) Explore SLPs' and clients' views on health literacy and client recall/memory and how these might be maximised.
- 2) Trial the use of technology/strategies which may be able to maximise health literacy and client recall/memory of clinical information.
- 3) Evaluate the outcomes of the technology/strategies employed from both the SLP's and client's perspective.

Ultimately, this study intended to provide insight and contribute to information about ways in which SLPs could overcome issues of health literacy skills and client recall/memory so that treatment effectiveness and efficiency could be improved.

There were three phases that were conducted in this study. The first phase served to explore SLPs' and clients' views on health literacy and client recall/memory and how these might be maximised. The second phase served to trial the use of technology/strategies which might be able to maximise health literacy and client recall/memory of clinical information and the third phase served to evaluate the outcomes of the technology/strategies employed from both the SLP's and client's perspective.

An overview of the research methodology is outlined in Table 2 below.

Table 2. Overview of research methodology

<b>PHASES</b>	<b>Phase One</b>	<b>Phase Two</b>	<b>Phase Three</b>		
<b>Research design</b>	Focus group discussions	Research Intervention (trailing combination of 3 strategies)	<b>Researcher</b> Simple observation	<b>Clients</b> Post-intervention semi-structured interviews	<b>SLPs</b> Post-intervention questionnaires & semi-structured interviews
<b>Tools</b>	Semi-structured interviews	Taking observation notes	Objective observation notes	Interview schedule	Self-administered questionnaire & Interview schedule
<b>Data sets</b>	Responses to open-ended and short questions	Observations to be discussed in post-intervention semi-structured interviews	Observations to be discussed in semi-structured interviews	Responses to open-ended and short questions	Likert scale responses and responses to questions (guided by responses to questionnaire)
<b>Nature of Data</b>	Qualitative	Qualitative	Qualitative	Qualitative	Qualitative
<b>Data analysis</b>	Immersion/crystallisation method	NA	Immersion/crystallisation method	Immersion/crystallisation method	Immersion/crystallisation method

## 2.2. Research design

An exploratory, inductive design was used, incorporating qualitative methods of data gathering. According to Babbie and Mouton (2004), exploratory studies are typically done to (a) satisfy the researcher's interest and desire to gain a better understanding, (b) test the viability of undertaking a more extensive study, (c) develop methods to be used in a subsequent study, (d) establish priorities for future research, and (e) develop new hypotheses with reference to an existing phenomenon. An inductive approach is taken to develop and build new interpretations or theories of certain areas of interest rather than approaching the research with an existing theory or research hypothesis (Babbie & Mouton, 2004).

### 2.2.1. Phase One

The literature review and the discussions with four experts of information technology informed the interview schedule for two focus groups with SLPs and two focus groups with clients (one with past-patients and one with caregivers). Their perspectives were considered and merged to generate possible strategies to be trialled in phase 2.

### ***Semi-structured exploratory interviews: defined***

According to Oppenheim (1992), the purpose of an exploratory interview is not to gather facts, but to develop ideas and potential research hypotheses. It is a method employed when a researcher is attempting to understand how a group of people or an individual feels and thinks about the topic of concern to the research. This concept, together with a semi-structured interview style makes up semi-structured exploratory interviews (Maxwell & Satake, 2006). According to Maxwell and Satake (2006) questions in a semi-structured interview are predetermined and presented in a systematic order. However, the interviewer has the freedom to occasionally deviate from the planned structure of the interview in order to explore a particular subject of interest in more depth. This allows more fluidity in the exchange of information and at the same time the interviewer can attain more knowledge from the interviewees. Concurrently, the ability to systematically analyse and compare responses to a scheduled list of questions is preserved. This was the interview style chosen to explore the views of all four focus groups on health literacy and client recall/memory and how these might be maximised.

### ***Focus groups: defined***

The main purpose of a focus group is to draw upon participants' knowledge, needs, feelings, attitudes, beliefs, experiences and reactions. Focus groups allow researchers to explore what participants think about particular issues and why they think that way (Gibbs, 1997; Kitzinger, 1995). Possible disadvantages are that results may not be generalised to a larger population due to small and less representative sample; privacy is lacking (which could lead to some participants being reluctant to voice their true opinions) and the existence of a "polarisation effect" is inevitable (which means that attitudes and opinions become more extreme after group discussions) (Neuman, 2006).

However, it was decided to proceed with the research designs as they were, because (to the researcher's knowledge) focus groups and discussions with both SLPs and clients around this topic had not yet been employed in combination in a study. An advantage of focus groups is that they are well suited for various kinds of problem-posing and problem-solving attempts. Participants can freely express ideas in a natural setting. (Kamberelis & Dimitriadis, 2008) and thus they allow access to SLPs and clients intersubjective experience about the problem under investigation (Kelly, 2006a).

Krueger (1998a) and Gibbs (1997) emphasised that the role of the moderator (researcher) in a focus group is significant in this case and they highlighted the importance of good level leadership and interpersonal skills which are required whenever focus groups are conducted. Last but not least, focus groups specifically have advantages for researchers in the field of health because they do not discriminate against people who have low literacy skills (as is needed in survey-research) and they can encourage participation from individuals who would be reluctant to be interviewed on their own (Kitzinger, 1995). Thus, focus groups were viewed to be the most appropriate design on the way to explore clients' and SLPs' views on health literacy and client recall/memory and how these might be maximised. Figure three provides an outline of phase 1 of the study.

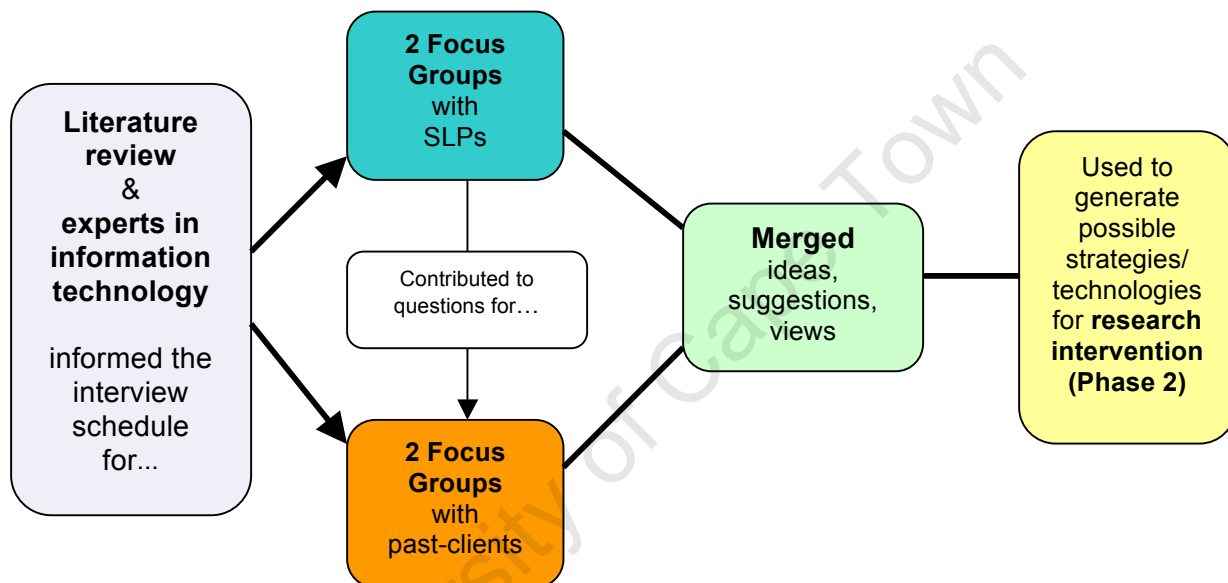


Figure 3. Outline of Phase 1 of the study.

### 2.2.2. Phase Two (research intervention)

#### *Case studies: defined*

It was suggested by Gerring (2007) that it is sometimes more helpful to attain in-depth knowledge of an individual example rather than fleeting knowledge about a larger number of examples. He also proposed that one can gain a better understanding of the whole problem by focussing on a key part of the research problem. The key part in these case studies was trialling the use of technology/strategies to maximise health literacy and client recall/memory of clinical information at a client's first consultation (given that this is typically where health literacy, recall/memory and other variables to compliance determine clients' understanding, eventual recall and resultant

adherence to treatment regimens). In respect of suggestions by Gerring (2007), fewer but more in-depth cases were chosen for this phase of the study.

During the actual research intervention, a single-subject (case study) design was used. Traditionally, the central focus of single-subject designs is the use of systematic methods for applying interventions and documenting their effects repeatedly in single individuals over a longer period of time (Maxwell & Satake, 2006). This study however only investigated cases at the first stages of their treatment. Yet, this type of design was used nonetheless because (a) it allowed for richness of data (detailed focus was on each participant at a crucial stage of their journey to better health) and (b) the researcher had a limited time frame to complete this research.

Furthermore, case studies serve best for contributing to research of an exploratory nature especially when a subject is encountered for the first time or is being considered in a fundamentally new way (Gerring, 2007). While considering the fact that there is little research available on the main topic in Speech-Language Pathology, it was sensible that a case study design was used to create a first line of evidence on this topic. Additionally, the design has been increasingly viewed by clinicians and researchers in the medical, behavioural and educational fields as a suitable means of contributing toward scientific knowledge (Maxwell & Satake, 2006). All the while, the researcher remained an objective outside observer, merely taking notes of occurrences that seemed significant to the individual cases (Babbie & Mouton, 2004). Figure four provides an outline of phase 2 of the study.

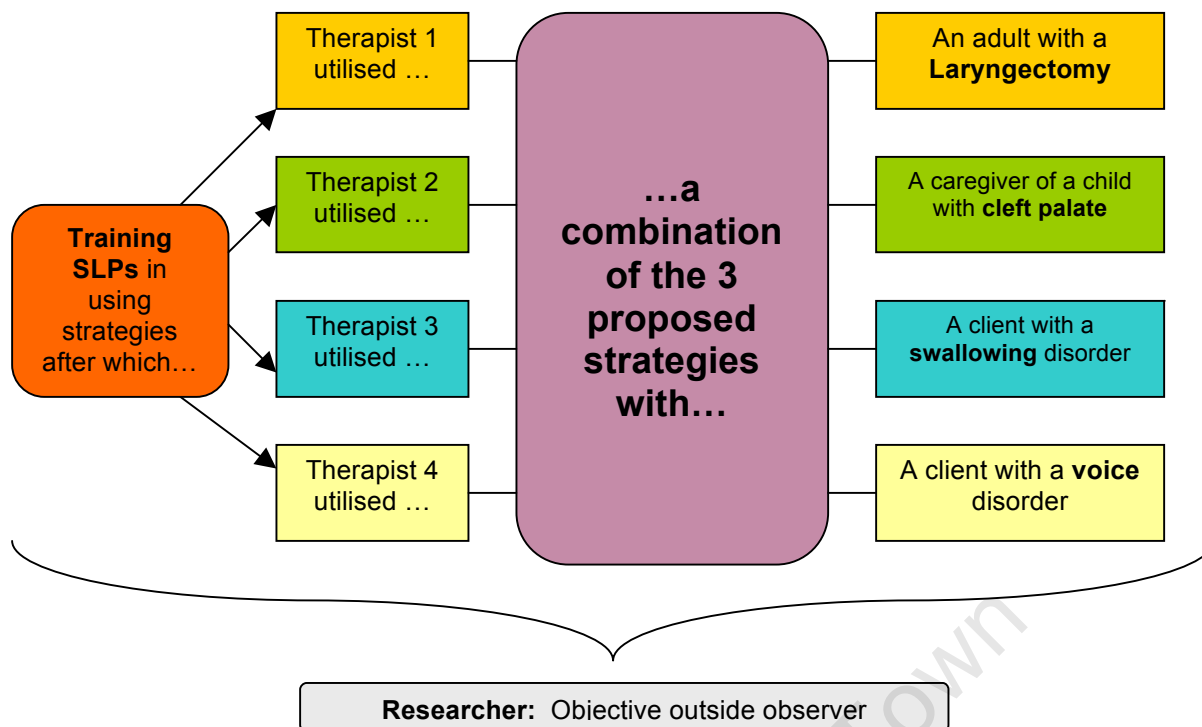


Figure 4. Outline of Phase 2 of the study.

### 2.2.3. Phase Three

According to Hoffman and McKenna (2006), evaluating the effectiveness of educational interventions is a central component in the process of informing clients. It can provide health professionals and clients with valuable information about the usefulness of strategies. This phase was conducted to evaluate the outcomes of the technology/strategies employed (during the period between the first consultation and the first follow-up appointment) from both the SLP's and client's perspective.

A key strength of the case study method is that it involves multiple sources and techniques of data gathering (Soy, 1997). Different sources of data (i.e. clients, SLPs and the researcher's own observations) as well as methods of data gathering (i.e. semi-structured interviewing and questionnaires) were employed. Thus, data triangulation and methodological triangulation, which refers to the utilisation of multiple data sources and methods to study a single problem respectively, were applied (Babbie & Mouton, 2004; Flick, 2006; Terre Blanche, Durrheim & Kelly, 2006).

Some advantages of questionnaires include that they are easier to analyse and results can be easily compared. However, disadvantages of a questionnaire are that it does not allow the researcher to

interact with respondents and they are limited in the depth to which the researcher is able to probe any response or allow digression from the set format of questions (Kanjee, 2006). Thus, SLP questionnaires were supplemented with semi-structured interviews. In addition, the researcher observed and noted occurrences that seemed significant to the individual cases (Babbie & Mouton, 2004).

### **2.3. Participants**

Authors such as Kahn and Pannbacker (2000), Toofany (2007) and Parker et al. (2003) suggest that clients or non-professionals be specifically involved in the development of educational and instructional methods as it is more likely that the outcomes will be consumer friendly. Ammenwerth, Brender, Nykänen, et al. (2004) also emphasise that a multi-disciplinary discussion is needed when discussing information technologies so as to promote multi-disciplinary involvement, visions and strategies to develop inclusive and effective health information systems through research. This is why information was drawn from SLPs and clients as well as the review of suggestions by experts of information technology.

There were various reasons for including SLPs as well as clients in this study. One of the reasons was because very little research has yet focused on investigating SLPs as well as clients as key role-players in the clinical process. As was outlined in the literature review, there are various barriers that are part of the everyday clinical process and it was viewed to be important to find researched strategies to overcome these barriers and thus improve health literacy and client recall/memory of clinical information (Glassman, 2007; Hester-Benitez-McCrary, 2006; Kagee, 2004). Another reason for including clients was because a reason for the lack of progress in compliance research is the absence of one crucial perspective, namely the client's perspective (Vermeire et al., 2001). There is also a lack of understanding of the way in which health professionals truly cope with various barriers when working with clients (Vermeire et al., 2001). Last but not least, few studies mentioned caregivers and the issues that come with low health literacy and problems in recalling/remembering clinical information. This is true even though Moon et al. (1998) found that regardless of their level of literacy skills, some parents' lacked knowledge and insight about their children's health and treatments. Parents need to be equipped with strategies to better understand and remember health information about their child's care because ultimately they are responsible for their child's development. For this reason the present study explored the research topic from the caregivers', adult clients' and SLPs' perspectives.

### **2.3.1. Study population**

Some clients and SLPs were recruited at a public hospital. Its service area extends 800 km from Cape Town. Many clients are poverty stricken, illiterate, and cannot communicate in Afrikaans or English which are the languages used by most health professionals (Fagan et al., 2002). Many of the clients that come to this hospital live in informal housing with no running water, flush toilets, electricity, or telephones. Many also reside a long distance from specialist services (Fagan et al., 2002).

Clients and SLPs were also recruited at another public hospital that serves a number of socioeconomically deprived and disadvantaged communities in the Western Cape Province (Donald, Sirgel, Kanyok, et al., 2000). It is the largest hospital in the Western Cape and the second largest hospital in South Africa. Over 2 million people receive healthcare from this hospital every year (Tygerberg Department of Health, 2005). Last but not least, some SLPs and clients were recruited at a community rehabilitation centre near Cape Town that serves clients with poorer socioeconomic backgrounds from most of Cape Town's surrounding areas (i.e. winelands and small towns).

### **2.3.2. Selection criteria**

#### ***Phase One: Focus groups with SLPs***

##### Criteria

SLPs had to:

1. currently be practicing around the area of the Cape Town because the focus of this study was on a particular population in Cape Town.
2. have at least one year post qualification experience in managing at least one of the disorders, which formed the focus of the study because it was preferred that SLPs had a clear understanding of the issues in health literacy and client recall/memory in these specific disorders.
3. be working with clients in public healthcare because had they only worked in private practice or private hospitals, they would typically not have seen clients from poorer socio-economic backgrounds with insufficient literacy skills and other variables which impact the success of treatment with these particular clients.

## ***Phase One: Focus groups with past-clients***

### Inclusion criteria

Past-clients had to:

1. have received treatment for either swallowing or voice disorders (including management of laryngectomies) or have a child who had received treatment for cleft lip and/or palate, voice or swallowing disorders (within the past six months) because these were the disorders that were specifically focussed on in this study. The time limit of six months was set because any details of treatment which had been provided before that time might have been forgotten (Ong et al., 1995; Stockler et al., 1993).
2. have a language other than English as their first language for the reason that differences in language between clients (who have a language other than English as their first language) and the majority of South African health professionals (who are proficient only in English and/or Afrikaans) can potentially affect their understanding and compliance with treatment (Drennan & Swartz, 2002; Kagee, 2004; Statistics South Africa, 2001). This would also apply to the proficiency of assistive materials that are provided in English only.
3. have poor socioeconomic backgrounds (i.e. clients who lived in informal settlements or rural areas) as these clients would be most likely to have experienced difficulties with compliance as a result of poverty (i.e. reduced self-efficacy, resources and high demands and stresses of daily survival, work and family life) (Kagee, 2004). It has to be noted here that even though Weiss and Coyne (1997) found that illiteracy is more common among people with low socioeconomic status, the health/general literacy skills of these particular participants were not screened. Doing so and excluding clients with average or higher health/general literacy skills could have been potentially restrictive when wanting to understand the problem under study from the views of a range of clients (with low socioeconomic backgrounds) in this limited research period.
4. be past-clients where the SLPs felt they had to make additional efforts to assure the client understood and remembered important clinical information.

### Exclusion criteria

Past-clients were not included when they had any additional cognitive, psychological or intellectual disorders as these were likely to affect their ability to give consent and their ability to express their opinion and perceptions (Ross & Deverell, 2004b).

## ***Phase Two: SLP who conducted the clinical part of the research intervention***

### Criteria

The criteria for an SLP who was to conduct the clinical part of the research intervention were the same as for those SLPs in phase 1. However, it has to be noted here that SLPs from phase 1 were not necessarily included as therapists in phase 2. Only some participants from phase 1 also took part in phase 2.

## ***Phase Two: Clients who took part in research intervention***

### Inclusion criteria

Clients had to have:

1. either a swallowing disorder, a voice disorder or a laryngectomy or they had to be a caregiver of a child with an unrepaired cleft lip and/or palate or a voice or swallowing disorder.
2. a language other than English as their first language for the same reasons that clients were included in focus groups.
3. low health and general literacy skills as determined through an informal health literacy screening tool (see Appendix C), adapted from Chew et al. (2004) which also included the use of informal cues suggested by Yin et al. (2007) (administration is discussed under methodology in section 2.4.). Here it was viewed to be important to know the level of health/general literacy skills of participants as clients with low health/general literacy skills would typically have fewer means to improve their health literacy skills (e.g. through the internet) or review health advice because they cannot understand or read healthcare materials (Arias, 2006; Ross, 2007; Sanders et al., 2007), thus indicating their need for additional strategies to assist them in this regard.
4. a poor socioeconomic background (i.e. clients who lived in informal settlements or rural areas) for the same reasons that clients were included in focus groups. The trialling of strategies to assist this group of individuals in health literacy and recall/memory was thus viewed to be most appropriate with clients who lived under those particular circumstances.

Bearing in mind the different opinions on whether health literacy skills and recall/memory are generally bound to age (Baker et al., 1998; Glassman, 2007; Ley, 1979; Kessels, 2003), it was decided that even though the age of participants was recorded, it was not considered a deciding

criterion for inclusion into the study at this point as the purpose was to identify strategies that would assist a client in health literacy and recall/memory regardless of their age.

### Exclusion criteria

Clients were not included when they had any additional cognitive, psychological or intellectual disorders as these were likely to affect their ability to give consent and their ability to express their opinion and perceptions (Ross & Deverell, 2004b).

### ***Phase Three: SLPs and clients who took part in research intervention***

This phase included the same participants as in phase 2.

### **2.3.3. Sample Size**

In phase 1, the total number of SLPs in the focus groups was nine. Kelly (2006a) suggests that a focus group should be composed of a minimum of six to twelve people. However, the groups had to be split into six and three for logistical reasons. The same applied to focus groups with past-clients where the total number of participants was eight but they were split into two groups of four.

In phase 2, a total of four participants were needed (i.e. one participant with a voice disorder, one with dysphagia, one with a cleft lip and/or palate and one with a laryngectomy). A small sample size was sufficient as this was an exploratory, qualitative study where the focus was on richness and detail of discussions rather than great volumes of diverse data (Maxwell & Satake, 2006).

### **2.3.4. Sampling method**

In phase 1 non-probability sampling was used (Babbie & Mouton, 2004) as this research was conducted in a situation where it was not possible to select the type of probability samples that are used in large-scale surveys (e.g. simple random sampling or systematic sampling). In this case, the researcher relied on available participants, which meant that participants were selected on the basis of their availability (Babbie & Mouton, 2004). In phase 2, purposive sampling was used and participants were selected based on the researcher's knowledge of their characteristics and the purpose of the study (Durrheim & Painter, 2006; Gerring, 2007; Maxwell & Satake, 2006).

### **2.3.5. Recruitment of participants**

#### ***Phase One***

Speech-Language Pathology Departments from three public hospitals in Cape Town were contacted to identify SLPs who would agree to participate in the focus groups. The SLPs, who met the criteria for participation in these focus groups, were contacted via e-mail. One mediator was chosen to liaise with respective colleagues, distribute information sheets/consent forms (Appendix D) and decide on a time and location which was suitable for all participants.

SLPs who participated in focus groups were given the selection criteria for past-clients. They were asked for suggestions and the respective contact details of potential participants. These potential participants were contacted telephonically. The study was described and they were invited to join the focus group at a time and location, which was suitable for them. After they agreed to participate, they were given an information sheet subsequent to which they signed a consent form (see Appendix E).

#### ***Phase Two***

Four SLPs who each had one of the disorders as an area of expertise were invited to participate in the study. The study and their role in it was explained. After they agreed to participate, they were given an information sheet and an opportunity to ask questions subsequent to which they signed a consent form (see Appendix F). Clients who were viewed to be suitable participants in the intervention phase of this study were identified jointly by the researcher and the SLP. While these clients were waiting for their consultation, the SLP introduced the study to potential participants and asked them for permission to be approached by the researcher. The study and its procedure were then explained to them and when they agreed to participate in the study, they were given an information sheet and a consent form to sign (see Appendix G). In cases where participants were not Afrikaans first language speakers, a trained interpreter was present (for consent form see Appendix H).

#### ***Phase Three***

This phase included the same participants as in phase 2.

### 2.3.6. Participant description

#### *SLPs in focus groups*

Table 3. Relevant background information on SLP focus group participants

Participants	Years of experience	Area of main clinical expertise
<b>FOCUS GROUP</b>		
Participant 1	2	Adult voice disorders and dysphagia
Participant 2	27	Dysphagia, laryngectomies, voice disorders, cleft lip and / or palate management
Participant 3	3	Adult voice disorders and dysphagia
<b>FOCUS GROUP</b>		
Participant 4	8	Voice disorders
Participant 5	5	Paediatric and adult dysphagia
Participant 6	14	Laryngectomies and cleft lip and / or palate management
Participant 7	19	Adult neurology and cleft lip and / or palate management
Participant 8	5	Paediatric and adult dysphagia
Participant 9	3	Adult neurology

All SLPs had a degree in Speech-Language Pathology and some were dual qualified (e.g. Speech-Language Pathology and Audiology). At the time of this research, most of them had been working in public tertiary healthcare for several years.

*Past-Clients in focus groups*

*Table 4. Relevant background information on past-client focus group participants*

<b>Participants</b>	<b>Home Language</b>	<b>Client received Speech Therapy intervention for...</b>	<b>Place of residence</b>
<b>FOCUS GROUP</b>			
Participant 1	Afrikaans (can speak and understand English)	Laryngectomy	Urban area: Cape Flats
Participant 2	Afrikaans (can speak and understand English)	Dysphagia and pre-operative counselling for laryngectomy	Urban area: Cape Flats
Participant 3	isiXhosa (can speak and understand English but are not fluent)	Voice disorder	Urban area: Informal housing
Participant 4	isiXhosa (with low level English language skills)	Voice disorder	Urban area: Informal housing
<b>FOCUS GROUP</b>			
Caregivers 5 and 6	isiXhosa (with low level English language skills)	Cleft palate	Urban area: Informal housing
Caregivers 7 and 8	isiXhosa (can speak and understand English but are not fluent)	Traumatic brain injury, dysphagia	Urban area: Informal housing

These clients had also been described by SLPs as clients that needed additional efforts to assure that they understood and remembered important clinical information. All participants came from an impoverished background.

***Intervention: Case studies***

Tables 4 detailing relevant background information of the four individual case studies and treating SLPs can be found in Appendix I.

## **2.4. Research process and data collection**

### **Phase One**

Initially it was decided to conduct one focus group with SLPs and one with past-clients. However, due to logistical complications, the researcher chose to conduct four different focus groups (i.e. two with SLPs and two with clients) instead. The approximate length of these focus groups was one to two hours, recommended by Kitzinger (1995) as the appropriate length of focus group discussions. This was to prevent fatigue and loss of concentration in participants whilst still yielding sufficient volumes of data.

There are three essential components to a focus group, which were adhered to during this study. The first component included introducing participants and the topic (in section 2.3. and 2.2.). The second component included clarifying the procedure of the focus groups while the third one required the researcher to induce active participation through using a semi-structured interview format (Kelly, 2006a). These last two components are described in the following sections.

#### ***Focus Groups with SLPs***

A trained interpreter who frequently offered his services to the Speech-Language Pathology department was employed for the client focus groups because the first language of most participants was isiXhosa, a language not spoken by the researcher. Questions were asked to elicit SLPs' views on issues around health literacy and client recall/memory of clinical information as well as the possible impact of these elements on the success of their treatment. Additionally, SLPs were asked to share information about strategies (if any) they might or do already use to improve health literacy and client recall/memory. Finally, suggestions for phase 2 of this study were welcomed. The outline and questions of the SLPs' interview schedule was developed with respect to: (a) suggestions by Kelly (2006a) and Krueger (1998a & 1998b) for the procedures in conducting focus groups, (b) the need for collecting information around the research topic and (c) ideas gathered from the literature review (Appendix J).

#### ***Focus Groups with Past-clients***

Qualitative data was further gathered in one focus group with past-clients and one focus group with caregivers of past-clients. Clients who had received some form of SLP treatment (in the past 6 months) for the selected disorders were asked to share their views on their ability to recall and understand the information that was provided to them. Furthermore, their suggestions on effective

strategies to enhance health literacy and client recall/memory of clinical information were elicited. In both of these client focus groups, consecutive interpreting was performed. This meant that there was a pause between the researcher's or participant's statements to allow for the interpreter's translation into the other language (Langdon, 2002). The outline and questions of the clients' interview schedule was developed with respect to: (a) suggestions by Kelly (2006a) for the procedures in conducting a focus group, (b) the need for collecting information around the research topic and (c) ideas gathered from the literature review and a study conducted by Chew et al. (2004) (Appendix K).

Consistency in procedures and questions in the SLP and client focus groups was necessary to ensure a degree of standardisation. Thus, the researcher carefully prepared for this part of the data collection in advance by outlining procedural steps and questions in an order which was followed rigidly. Some questions and procedures might have shifted from what had been learnt from previous groups (i.e. saturation occurred or questions were difficult to understand). However, the core questions and basic procedures were adhered to at all times (Krueger, 1998b). This created the advantage of maintaining a certain amount of comparability across groups while allowing for emergent needs of research to be explored in every individual group (Morgan, 1996).

The researcher was aware of the risks (outlined in section 2.2.1.) which is why careful preparation and foresight in the discussions was needed. The key was to probe for details while keeping conversations from drifting, making sure every participant had a chance to speak and avoiding the provision of personal opinions/involvement (by the researcher) so as to prevent steering participants towards any particular opinion or position (Gibbs, 1997; Krueger, 1998a). Furthermore, it was important for the researcher to distinguish between individual opinions expressed in spite of the actual group consensus (Kitzinger, 1995). Thus, special attention was given to minority opinions and examples. To view the degree of structure imposed by the researcher (Morgan, 1996), see Appendix J and K for specific procedures and interview schedules.

## **Phase Two**

Information gathered from the focus groups and the literature review was used to design a combination of three strategies/methods, which was viewed to be most useful in maximising client recall/memory. During focus group discussions it was noted that one strategy was often not enough on its own. Thus, it was decided that the most appropriate three strategies would be combined and

trialled with four clients. This decision was also made in light of suggestions by Kagee (2004) and Vermeire et al. (2001) who emphasised that the complexity of the problem of client non-adherence suggests that no single solution was likely to be helpful and that strategies were actually more functional when combined. It was decided to provide three strategies to address client health literacy and recall. These were (a) audio-recorded information in the form of a CD or cassette together with (b) the possibility of sending a “please call me” message from a client’s mobile phone to the SLP after which (c) they would be contacted telephonically to allow for routine reminders and a possibility for discussion and feedback post-consultation.

The task of selecting cases was a matter of achieving two objectives: namely choosing cases that were (a) representative (at least to some degree) of the population under study, and (b) that provided variation along the variables that were of interest in the study (Gerring, 2007). Thus, cases that were chosen fit the inclusion criteria closely and they ranged from being an extreme case to three cases that were most-similar (Babbie & Mouton, 2004; Gerring, 2007). An extreme case is also a rare case, one that is considered to be most definitive of some phenomena of interest (i.e. low health and general literacy, poor socioeconomic background). Most-similar cases are similar in most aspects (i.e. health and general literacy skills or socioeconomic backgrounds) but they exhibit surprisingly different outcomes (Gerring, 2007).

In order to reach an understanding of a potential participant’s health literacy skills, an informal health literacy screening tool was used before they entered the consultation (Appendix C). This screening tool consisted of eight questions and for each question, the participant was required to rate the occurrence of a particular situation that requires good health literacy skills (i.e. whether it occurred *always*, *often*, *sometimes*, *occasionally* or *never*). Participants were excluded when they reported high level health literacy skills (i.e. when participants scored a situation occurring *occasionally* or *never* more than half the time). Even though it was revealed in the literature review, that people with high health and general literacy skills also experience difficulties with compliance (Glassman, 2007; Moon et al., 1998), it was decided to only focus on individuals who were at “high-risk” for non-compliance because of the limited scope of this study and the great need for research to generate ideas and insight into how health literacy and recall of information can be maximised in clients who are at “high-risk”.

### ***Intervention (trailing of combined strategies)***

Firstly, SLPs were familiarised with the procedures of the three chosen strategies to prevent potential problems from occurring during consultations. This technical run-through also served as an opportunity for the researcher to test the equipment in the different working environments. If SLPs were not confident that they would be able to use the proposed strategies by the end of this training session, it was suggested that the researcher would assist in the technical/practical aspects of the strategies. This was based on Doak, Doak and Meade (1996), who found that it initially took time to train professionals in the development and use of technological interventions and thus the researcher was aware that it might have taken more than a few practice sessions for SLP participants to perfect the procedures of these different strategies.

Each SLP conducted an initial assessment as per their routine clinical procedure and made recommendations. Whenever important information and recommendations were to be provided, the SLPs gave a signal to the researcher to audio-record that information. When all information was recorded and the consultation was concluded, this audio-recording was given to the client in addition to low tech materials that the SLP usually provides. The purpose and use of this recording together with the use of the “please call me” function of their mobile phone was explained by the researcher. Clients were also given a date for a follow-up appointment (after at least three but not more than six weeks). The reason for keeping the time interval between phase 2 and 3 below six weeks was because it had been reported that recall decreased over time even when strategies were used to improve recall of clinical information and health literacy (Ong et al., 1995; Stockler et al., 1993). This time period gave the client an opportunity to independently manage their own health while using the proposed strategies. The researcher made simple observation notes on information from the assessment and recommendations so as to have a record of each participant’s treatment regimen for comparisons with the SLPs observations in phase 3 and later use in data analysis.

### **Phase Three**

Firstly, clients were interviewed through short semi-structured interviews to probe more deeply into the positive or negative experiences of clients after having used the proposed strategies (see Appendix L for details on the interview schedule). The outline and questions for the interview schedule with clients were developed using suggestions from Kanjee (2006) and Oppenheim (1992) on how to conduct exploratory interviews. The rationale behind the questions was the need for gathering data (feedback) on the proposed strategies for enhancing health literacy and client

recall/memory of information. The questions were also based on ideas gathered from the literature review and a study conducted by Ammenwerth, Brender, Nykänen, et al. (2004) and Chew et al. (2004). After the interview schedule was first completed, it was checked by the researcher's supervisor in order to ensure that the procedure was in order and the questions were appropriate for this phase of the study. Participants were encouraged to take their time when answering questions so that they could give their true opinion. They were also encouraged to ask questions for clarification. Participants were reminded that the interview would be recorded. It was further explained that the contents of this interview were absolutely confidential and that the information identifying *them* as respondents would not be disclosed under any circumstances. Convergence was accomplished by asking the same sets of questions for investigating the same variables across cases (Babbie & Mouton, 2004). At the same time, each case was treated as an individual case with its own set of outcomes and circumstances (Kelly, 2006a).

Subsequently, a questionnaire using a Likert scale and open-ended questions (see Appendix M for questionnaire) as well as a subsequent semi-structured interview was conducted with SLPs. The purpose of the questionnaire was to assist in organising data and further in-depth discussions while allowing SLPs time to think about their responses. The subsequent interview gave the researcher an opportunity to probe more deeply into the positive or negative experiences reported by the SLP after having used the proposed strategies. The outline and questions for this questionnaire were developed with respect to: (a) suggestions by Kanjee (2006) and Oppenheim (1992) on how to develop a questionnaire, (b) the need for gathering data (feedback) on the proposed strategies for enhancing health literacy as well as client recall/memory of information and (c) ideas gathered from the literature review and the study by Ammenwerth, Brender, Nykänen, et al. (2004). After it was first completed, it was run by the researcher's supervisor for approval.

Participants had to be interviewed in this order so that the client's view and other significant information was known to the researcher before interviewing the SLP. Through this, discussions could be further enriched and the researcher's simple observations (from phase 2 and 3) checked, verified or opposed by SLP. This was done with the intention of gaining more insight and feedback with regards to problems that surfaced or specific instances that occurred which would have gone unnoticed otherwise (Babbie & Mouton, 2004).

Focus group discussions and individual interviews were audio-recorded with participants' permission, to ensure that no data was lost. The discussions in phase 1 did not take longer than 1 hour and the interviews in phase 3 did not take longer than 45 minutes per participant.

## 2.5. Analysis

Terre Blanche et al. (2006) suggest an immersion/crystallisation style to be used when analysing qualitative data, which involves becoming familiar with phenomena, reflecting on them and then writing an interpretation (i.e. the results and discussion section). Important underlying dimensions and patterns were to be discovered in this process (Polit & Hungler, 1993). For this purpose, data of focus group discussions and SLP and client individual interviews were transcribed (see Appendices N, O, P and Q for case study transcripts). The chart in Figure five gives an outline of the analysis procedure.

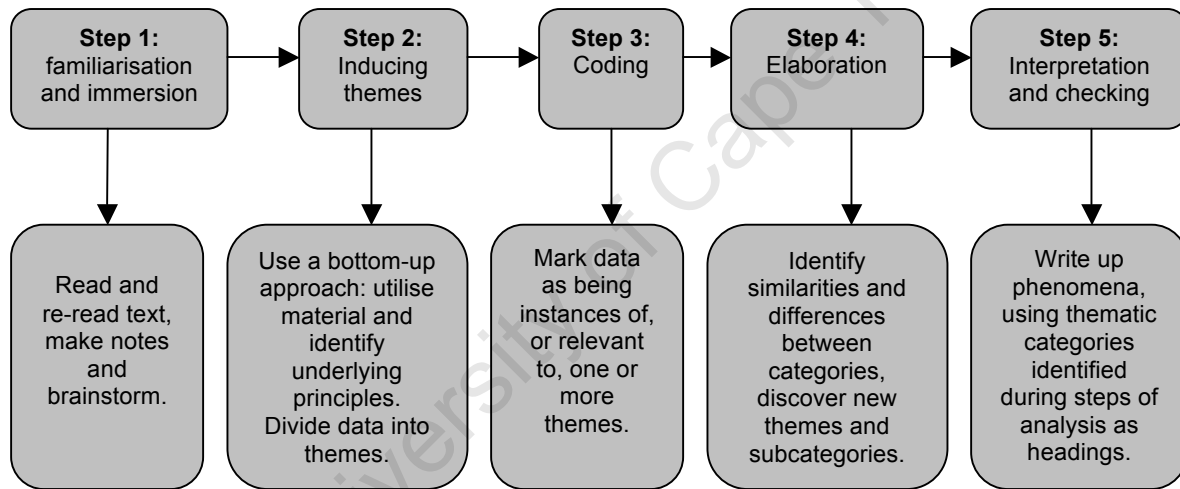


Figure 5. Outline of method for analysing qualitative data (Adapted from Terre Blanche et al. 2006).

### Phase One

According to Kitzinger (1995), when analysing focus group data, it is important that the researcher assembles and compares discussions of specific themes. Thus, data gathered from the focus group interviews were sorted according to SLPs' and clients' views on (a) issues around health literacy and client recall/memory of clinical information and (b) the possible impact of these issues on the effectiveness of treatment. In addition, data was sorted according to suggestions and views on

strategies to maximise health literacy and client recall/memory and new and emergent themes were identified.

## **Phase Two**

This was an intervention phase. Thus, no data analysis was conducted in this phase.

## **Phase Three**

The ultimate goal for phase three was to explore participants' views and perspectives on the strategies used to improve health literacy and client recall/memory of clinical information. Patterns that emerged from the data had to be identified and matched with patterns in the literature review/other scientific knowledge so as to enhance internal validity (Yin, 1994). All the while, the researcher had to generate informative explanations about the cases under study (Yin, 1994). Themes that were originally suggested by McClement and Hack (1999) as well as Ammenwerth, Brender, Nykänen, et al. (2004) were considered, adapted and combined to form six themes against which the data were analysed. The themes were:

- (a) Improvement of knowledge and recall of medical information (long- and short-term);
- (b) Satisfaction related to the value that is placed on the strategies or the extent to which the participants found them to be helpful;
- (c) Is the combination of the strategies usable in the intended environment and for the intended purpose? If not, what are SLPs' and clients' attitudes towards using the strategies in future and suggestions on improvements?
- (d) Do users need more training and guidance in order to use the strategies appropriately?
- (e) Possible effects that the combination of these strategies have on structural or process quality (e.g. time saving, clinical workflow).

## **Summary**

This was an exploratory study with qualitative methods of data gathering. In phase 1, data was gathered through focus group discussions with Speech-Language Pathologists and clients, who had received Speech-Language Pathology treatment in the past. In phase 2, the data from phase 1 was used to trial three combined strategies in four studies with clients who were receiving Speech-Language Pathology treatment (for the disorders under focus) at the time of this research. In phase

3, data was gathered through questionnaires and semi-structured exploratory interviews to evaluate outcomes of the strategies from clients' and SLPs' perspectives. All the while, the researcher made objective observation notes. Data was analysed qualitatively through an immersion/crystallisation method.

## **2.6. Assuring Trustworthiness and Rigour**

The key principle of good qualitative research is the notion of trustworthiness. There were a number of steps that had to be taken to assure (a) dependability, (b) credibility, (c) confirmability and (d) transferability (Babbie & Mouton, 2004).

### **Dependability**

“Reliability refers to the consistency of measurement – the extent to which the results are similar/repeatable over different forms of the same instrument or occasions of data collection” (McMillan & Schumacher, 2001, p. 244). However, it was expected that groups and individuals would behave differently and express different opinions in changing contexts. Thus, it was proposed that in place of the principle of reliability, findings should be dependable. Dependability is accomplished through careful documentation of procedures for generating and interpreting data (Schwandt, 2001). To ensure this, the researcher provided comprehensive background information about the focus groups and four case studies, the research setting as well as the methodology, data collection and analysis (as was discussed in sections 2.2., 2.3. and 2.4.).

When administering procedures and measuring and assessing results, intraobserver reliability was assured by a high degree of internal consistency in the researcher herself (Maxwell & Satake, 2006). This involved constant evaluation of own thoughts and attitudes as well as being open and subjective during the entire research process (McMillan & Schumacher, 2001). In addition, peer debriefing, as suggested by Babbie and Mouton (2004), was done with the supervisor of this study, who is an experienced SLP and has a general understanding of the research topic, but was outside the context of this study. She reviewed and challenged the researcher's decisions and assisted in understanding the research process to ensure that the procedures were accurate and the findings valid. Thus, dependability of the study was assured.

## **Credibility**

Validity in qualitative research has to do with research description and explanation i.e. whether or not the research description and explanation is credible (Denzin & Lincoln, 2003). There were various steps that needed to be taken to ensure that the research and data were credible. Firstly, interviews were audio recorded so as to collect mechanically recorded data, which gave a more objective form of data (i.e. precise and detailed responses from participants) compared to that obtained from short handwritten records of responses (McMillan & Schumacher, 2001). Secondly, there had to be a certain degree to which interpretations and theories had mutual meanings between the participants and the researcher (McMillan & Schumacher, 2001). Thus, the researcher attempted to clarify any misunderstandings during the interviews to ensure that the participants' responses were correctly interpreted by the interviewer. Finally, the transcripts were checked by an experienced and qualified SLP who had no vested interest in the study. There was 98% agreement between the researcher's and the proof reader's transcriptions.

Furthermore, a combination of research strategies were used to enhance credibility (McMillan & Schumacher, 2001). The researcher made use of verbatim accounts, mechanically recording the data, allowing the participants to select a language they were competent in and utilising predefined questions and procedures with all participants. Additionally, use of different sources of data (i.e. clients', SLPs' and the researcher's own observations) as well as methods of data gathering (i.e. interviewing and questionnaires) was made (i.e. data and methodological triangulation).

To further enhance credibility, extraneous variables had to be controlled (Maxwell & Satake, 2006). Four SLPs who naturally all differed when it came to their style of providing therapy were included in phase 2 of this study. These differences in the style of providing therapy could have had an impact on results. However, the researcher made note of any of these differences and discussed their possible impact on results when reporting on the data. As mentioned before, the SLPs themselves had no vested interest in the study, which contributed to objectivity.

## **Confirmability**

In order to create a basis for transferability and allow other researchers to use the findings to make comparisons with their own work, the research report described the research process, choices of methods as well as the research situation and context in detail (sections 2.2. and 2.3.), thus assuring a degree of confirmability (Babbie & Mouton, 2004).

## **Transferability**

Transferential validity (Smaling, 1992 as cited in Kelly, 2006b) is also an important feature in qualitative research. It refers to the ability of the research report to grant answers in, and transferability of findings to other contexts. Unfortunately, the sample of participants used in this study was subject to availability of clients and it may therefore not be a representative sample. Furthermore, there was specific focus on selected disorders and clients at selected healthcare facilities. Thus, the findings were not generalisable to all disorders in the SLP profession, or any context above or beyond the context in which this study was conducted. Transferability of findings would only be possible to clients and contexts similar to this research.

## **2.7. Ethical Considerations**

This study was granted ethical approval by the University's Research Ethics Committee (REC REF: 116/2008), before it was conducted in accordance with the Declaration of Helsinki (Benatar, 2002). The basic principles that were followed were the principle of respect for people (which includes confidentiality and their autonomy), the principle of non-maleficence/beneficence and the principle of justice.

### **Confidentiality and representativeness of samples**

The most salient ethical problems of this study were confidentiality in focus groups and representativeness of the sample. Measures were followed to assure confidentiality in all phases of the study. A coding system was used to ensure that participants' names were not used on any forms likely to be seen by persons other than the researcher. The researcher refrained from making the information accessible to other parties (Polit & Hungler, 1993). Audio recordings and transcripts were kept in a locked and secure location. No recorded audio material or transcripts were shared with persons other than the researcher, without consent of the participant (Behi & Nolan, 1995). However, interactions in the focus groups involved some form of self-disclosure by participants. All participants in the focus groups were asked to maintain confidentiality, even though this could not be guaranteed as it was possible that some participants might have shared what was discussed outside of the group.

There was a risk that SLPs taking part in the focus groups would feel embarrassed if his/her practice of giving health information was lacking or poorly done. However, the purpose of this study was to generate valuable knowledge for SLPs to use in their management and thus, the benefits outweighed the risks, satisfying the principle of non-maleficence/beneficence (Loue, 2000).

The study attempted to make use of a representative sample of participants. However, the sample of participants used in this study was subject to certain characteristics and availability of clients and therefore the sample was not entirely representative of the population of clients living in Cape Town. Nevertheless, the sample was appropriate for this study and it was also representative of the client population that visits public hospitals and rehabilitation clinics. Thus, the risks and benefits of the study would have been carried by members of that same population, in keeping with the principle of justice (Loue, 2000).

## **Consent**

Bankowski, Bryant and Last (1993) highlighted the importance of informed consent in the ethical justification of research involving human participants. Informed consent entails notifying the research participant of the purpose and procedures of the study as well as explaining the concept of confidentiality (Gibson, Schwartz & Sandenbergh, 2002). Each participant had to be “legally competent”, “informed” and “comprehending” (Bankowski et al., 1993) before they were invited to voluntarily sign a consent form. In the case where an individual could not write, they were able to sign with a thumbprint. The consent forms were read out and explained to them in the language which they preferred. A trained interpreter was used for this to ensure that the content of the consent form was translated accurately (Human Subjects Division, 2006).

According to the Medical Research Council (2001), consent should not be induced by fear, deceit or undue influence. Participants were assured that participation in this study was voluntary and that whether or not they decided to participate in this study, the quality of treatment they or their child was entitled to would not be jeopardised. Furthermore, they were informed that they could withdraw from the study at any time without giving reasons and without it having negative implications for their treatment. Thus, the study met the principle of autonomy (Lo, 1995).

No incentives were given for participating in this study. Participants were compensated for any additional travelling costs, as a result of travelling to and from the research site. Furthermore, the

study did not directly involve any vulnerable parties such as prisoners, the mentally challenged, physically or mentally ill clients, children, substance abusers and unconscious or terminally ill clients (Ross & Deverell, 2004b). At no point did the study involve research participants who were under the legal age of 21.

A range of activities using formal and informal media will be used to circulate the study findings, and explore follow-up possibilities. For example, findings should be disseminated through journal publication or conference attendance and discussions with other SLPs. Having outlined the aims and objectives as well as the research design and procedures of this study, it is now appropriate to present and discuss the data collected in phase 1 and 3 of this study.

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## Chapter 3: Results and discussion of Phase One

This chapter is divided into two sections. The first section explores SLPs' and clients' views on health literacy and client recall/memory in Speech-Language Pathology and the second section explores SLPs' and clients' views on how these might be maximised. The ultimate purpose of this phase was to merge perspectives from all participants in phase 1 to decide on strategies that were to be trialled in phase 2. The first focus group was the group made up of three SLPs and the second focus group was the group made up of six SLPs. Thus, when referencing SLP participants of the first focus group and second focus group, they will be referred to as participants of FG 1 or FG 2. The same applies to the first and second client focus groups (each made up of four participants).

### 3.1. SLPs' and clients' views on issues around health literacy and client recall/memory of clinical information

The following Table provides an outline of the sub-themes that were extracted from the data of phase 1. These are factors which were identified as influencers of clients' compliance with treatment regimes.

*Table 6. Outline of the sub- themes that were extracted in phase 1*

<b>Issues raised</b>	
<b>FACTORS</b>	<b>BRIEF DESCRIPTIONS</b>
<i>Factors related to health professionals</i>	
<b>Too much complex information from various professionals provided at first appointment</b>	Clients feel overwhelmed by the vast amounts of information from various health professionals which they need to process especially at the beginning of their treatments.
<b>Health professionals overestimate client understanding and recall of information</b>	When SLPs do not look out for misunderstandings of treatment information and guidelines or a lack of participation by the client or family members, they might assume that clients have grasped all that was discussed.

<i>Factors that exist between SLPs and clients</i>	
<b>Dynamics of client-health professional relationship</b>	Clients' anxiety and reluctance to make their needs known can be attributed to the dynamics of the relationship between clients and health professionals, i.e. clients being intimidated by the knowledge of health professionals and being uncomfortable in the clinical environment.
<b>Effects of mistrust and dissatisfaction with intervention</b>	Depending on a client's level of mistrust of the health professional's advice or satisfaction with interventions, the outcomes of treatment may be affected.
<b>Differences in clients' and health professionals' priorities</b>	If the readiness to act on health advice is high and the negative aspects of recommendations are seen as relatively weak, adherence to that advice is more likely. However, if the potential negative aspects of recommendations are seen as strong, the readiness to act on health advice is low and clients may be less likely to act on health advice. Priorities also depend on socioeconomic factors i.e. stressors which prevent clients from giving their full attention to the management of their disorder.
<i>Client-specific factors</i>	
<i>Personal factors</i>	
<b>Levels of motivation and insight</b>	Insight, which impacts clients' understanding and the interest in attending and following recommendations, might be influenced by the motivation to making a specific health problem a priority.
<b>Sense of role, responsibility and expectations in healthcare</b>	In addition to motivation and insight, some clients also do not understand that they have a very important role to play in their (or their child's) healthcare.
<b>Effects of emotional variables</b>	During consultations there are vast amounts of information to be processed in the presence of confounding variables such as stress, anxiety and an intimidating clinical environment. Outside of the clinical environment, the presence of stress and anxiety could also prevent clients from successfully complying with treatment.

<i>Factors related to health information exchange and related variables</i>	
<b>Clients adhere to what <i>they</i> think works best</b>	Clients might be too overwhelmed by vast amounts of “new” information on how to care for themselves or their child. Thus, when in doubt after not having understood or remembered information, they will proceed with what they think is most accommodating to their (or their child’s) immediate health needs (even if it might not be the best approach).
<b>Low health literacy skills and recall affect the success/duration of treatment regimes resulting in various consequences</b>	Clients lose hope when there is no success in treatment and SLPs become frustrated and sometimes need to spend more time with these clients to correct what was misunderstood or not remembered (which further adds to SLPs intense workloads).
<b>The issue of literacy skills</b>	Many clients cannot read and also do not have a family member who can assist. Clients who are not fortunate enough to make additional use of the internet for example to make informed choices and assist them in learning and managing their own health, have to rely solely on the verbal (and sometimes written) information that SLPs and other health professionals provide.
<b>Consequences of non-compliance and recommendations are disregarded, misunderstood, forgotten or too difficult to adhere to</b>	<p>Clients’ non-compliance could also be attributed to possible disregard of recommendations or difficulties in understanding or acknowledging the consequences of non-compliance.</p> <p>When a client does not understand what and why they are following recommendations, there will be less compliance.</p> <p>Clients may also be unaware that they have misunderstood or forgotten information and as a result may become frustrated or dissatisfied because they do not see any success in following recommendations. They may also be regarded as non-compliant because SLPs do not see any progress.</p> <p>Advice and treatment provided by SLPs may be too difficult to adhere to because it is typically more abstract, complex, descriptive and long-term than the information provided by medical doctors whose advice is short-term and typically focuses on immediate physiological needs.</p>
<b>Lack of access to, and awareness of general healthcare and Speech-Language Pathology services</b>	Clients lack awareness of general health and various (other and Speech-Language Pathology) services as well as the consequences of Speech-Language Pathology disorders which impact their ability to seek appropriate advice and follow recommendations appropriately.

<i>Interpersonal factors</i>	
<b>The presence of support structures</b>	Compliance and support complement each other. When an individual does not have the support from the family or a health professional, their compliance may be negatively affected.
<b>Loss of carry-over of information between caregivers</b>	Information gets lost between caregivers. The person who brings a client to healthcare facilities is not always the primary caregiver of that individual. It is between these parties that information can get lost.
<i>Clinical variables</i>	
<b>Differences between disorders and compliance with treatment regimes</b>	Depending on types of disorders, the amount of clinical information and recommendations that need to be understood and recalled will vary, causing some clients to be able to remember more or less than others which ultimately may affect compliance and treatment outcomes.
<b>Issues of bilingualism and lack of trained interpreters</b>	In many parts of South Africa, clients that are seen in public health-care facilities have little or no English/Afrikaans language or literacy skills and most of the time interpreters are not available (when they are, they are mostly untrained). Thus, clients' abilities to understand and recall information in order to comply with treatment regimes are compromised.

The following section discusses SLPs' and clients' views on issues around health literacy and client recall under five themes. These are factors related to health professionals, factors that exist between SLPs and clients, client-specific factors, interpersonal factors and clinical variables. Sub-themes to each theme are further discussed.

### **3.1.1. Factors related to health professionals**

#### ***Too much complex information from various health professionals provided at first appointment***

There was unanimous consensus among SLPs that they frequently deal with clients who have difficulties understanding and remembering clinical information and recommendations. One reason that SLP participants provided, was that many clients already do not understand or remember information provided by other health professionals prior to arriving at their consultation with the SLP. SLP participants of FG 2 further elaborated on the occurring frequency of this issue by explaining that they come across clients daily who do not know the reason for referral or the

diagnosis. Furthermore, SLP participants reported that in addition to information provided by the SLP, general information from other health professionals frequently needs to be clarified. SLP participants of FG 1 explained:

**PT 3:** Yeah... I'd say daily we see people like that...

**PT 2:** Yes they don't know...

**PT 1:** The majority of our voice patients that get referred from ENT, the first thing they, I ask them all the time or I tell them it's not cancer and they're so relieved because they thought that it was cancer the whole time when really they were referred to us because of a small nodule.

**PT 2:** But even families of patients that have had strokes they come here and they really have little knowledge... (...)<sup>5</sup>

**PT 1:** What about your moms at cleft palate?

**PT 2:** They also come with no understanding, absolutely, so as a first off they come with absolutely no understanding...so I would say that's frequent...

One SLP participant of FG 2 went as far as to say:

I mean how many times do patients come here and they don't know why they've been sent?

This provides an interesting perspective into these SLPs' roles as mediators and sources of clarification of general health information provided outside of their consultation. Nevertheless, when all is provided in one consultation, it will inevitably amount to a mass of information that the client needs to not only understand but also remember. This further adds to research findings of Fitzner and Fielding (1994), Flocke and Stange (2004), Ley (1979), as well as North et al. (1992) who found that the provision of too much and disorganised information can make it difficult for a client to recall information.

SLP participants of FG 2 provided another reason for clients' difficulties in understanding and remembering information when they highlighted that some complex disorders (e.g. cleft lip and/or palate or dysphagia) require SLPs to initially provide a lot of information and recommendations. As some clients can only come once a month, or there is the perceived risk that they may never return, these SLPs provide all information at once. Furthermore, SLP participants of FG 2 explained that out of fear that their clients will not comply, they will sometimes go as far as "threatening" clients to comply. They explained:

**PT2:** (...) So you explain all of this, you explain the diagnosis and you give them all these millions of recommendations and what's going to happen in the future and if this happens when to call. And I think it's a bit overwhelming for parents to hear all of this information and diagnosis...

**PT1:** From various professionals.

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<sup>5</sup> Hereinafter this symbol (...) will be used when unnecessary speech was excluded.

**PT2:** ... at like one session, and I think that sometimes...(...) I mean there's a lot of things going on (...) and that's the thing is that you need to put all the risks like; if you don't come, what will happen as well. So you almost like threaten them...

This could aggravate the already elevated feelings of anxiety and stress that clients experience (Flocke & Stange, 2004) and it may be overwhelming to some clients, especially when they see more than one health professional during their visit to the hospital. The question is whether or not these clients actually remember most of the information that is provided to them in these situations. Furthermore, when clients attend appointments irregularly, there is infrequent contact with the SLP during treatment periods which hampers the flow of feedback, information and support between both parties. Anderson et al. (1979 as cited in Kessels, 2003) reported that 40-80% of medical information presented by health professionals is forgotten immediately, and nearly half of the information that is actually remembered is incorrect. These facts cannot be ruled out when clients receive health information under the above circumstances.

Flocke and Stange (2004) who found that the amount of time spent explaining and discussing important health information and recommendations, correlated with the amount of information that was recalled by the clients. SLP participants of FG 2 explained that, because of the nature of Speech-Language Pathology management which typically lasts for more than one session and time spent in a session is never less than 15 minutes, clients have more time to ask questions. Client participants all attended consultations with a SLP which lasted from 30 minutes to an hour. They explained that this was more than enough time to spend with the SLP. There was time to ask questions and to learn about various aspects of Speech-Language Pathology treatment as well as other medical treatments which facilitated their understanding of the vast amount of information that they needed to process. Client participants of FG 2 confirmed that:

**PT3 and PT4: (interpreter)** That's what they like about therapist. Therapist has got enough time and can explain to you clearly what you must do so they feel so comfortable to be with the therapist...(…)

One client participant regularly attends appointments and he explained that initially he was anxious about his laryngectomy procedure. However, having time and many opportunities to ask questions assisted him in understanding and remembering various procedures and future management of his condition, thus reducing the anxiety that he felt. The fact that some Speech-Language Pathology appointments may last longer than an average appointment at the general practitioner, is therefore one advantage to clients who feel overwhelmed by the vast amounts of information which they need to process, especially at the beginning of their treatments.

### ***Health professionals overestimate client understanding and recall of clinical information***

A study by Leiter and Windsor (1996) showed that SLPs significantly overestimated the level of compliance, understanding and recall in clients. SLP participants of FG 1 disagreed on this topic; some felt that SLPs frequently overestimate clients' understanding and recall especially when SLPs use complex terms without explaining them in lay vocabulary. However, another SLP from that group felt that years of experience in working with a specific population assists in providing clinical information in a way that is appropriate for clients who are at "high-risk". Health professionals do have different levels of experience (Bastable, 2006) and these differences may cause some SLPs to be more prone to assuming their client has understood and will remember the information that was provided. One SLP participant provided an example of this when she explained that if clients and family members are uninvolved during consultations and an SLP does not look out for misunderstandings of treatment information and guidelines, they might assume that clients have grasped all that was discussed. When asked about the implications of this issue, SLP participants explained that clients lose trust because they feel that health professionals are not interested in assisting them in comprehending and remembering information. Clients may also become too overwhelmed by the pressure of achieving therapy goals which they had difficulty understanding and recalling in the first place. One SLP participant of FG 2 added:

...(they become) overwhelmed and they just start feeling quite helpless, that they're never going to achieve what you asked of them.

As a result, clients may "switch off" during consultations which ultimately becomes detrimental to their compliance with treatment (Fitzner & Fielding, 1994).

SLP participants of FG 2 continued to address this issue from the SLPs' point of view. They felt that because it was very difficult to accurately judge a client's level of insight, they are more comfortable when assuming a certain level of understanding from a client rather than talking down to them as though they were less intelligent. They also explained that it could be potentially embarrassing for a SLP to speak in over-simplified language with a client who might ultimately be offended by that gesture. This further adds to research of health professionals' differing ways of approaching the provision of information to clients and their families (Tooth & Refshauge, 2006). The dilemma of whether or not to assume a client's level of insight could potentially have serious consequences when clients leave the consultation without having understood and remembered important information and guidelines (Low et al., 2001). Alternatively, to avoid overestimating clients' understanding and recall of information, SLPs could provide their clients with assistive information

aids while acknowledging clients' individual learning styles and ways of thinking, learning and problem-solving (Hoffman & McKenna, 2006). Materials might range from written to audio-visual or they could be strategies such as the "teach-back" method (Osborne, 2008c).

### 3.1.2. Factors that exist between SLPs and clients

#### *Dynamics of client-health professional relationship*

SLP participants of both focus groups ascribed clients' stress, anxiety and reluctance to make their needs known, to dynamics of the relationship between both parties, being intimidated by the knowledge of health professionals and being uncomfortable in the clinical environment which may lead clients to take up a more passive role in consultations (Cilliers, 2005; Marfo, 1993). One SLP participant of FG 1 explained:

They're too scared to tell you they haven't understood... so they go nod, nod, yes, yes doctor and they walk out not having understood a word (...) and unless you really probe and you're really alert and careful and give opportunities for questions you'll think they've understood and they won't tell you that they haven't.

This concurs with the statement by Marfo (1993) who explained that when it comes to the South African client population, there is an apparent tendency to accept information noninteractively even when the information may not be entirely understood. Contrary to this, Ewart and Till (1998) noted that clients' passivity during consultations actually reflects their acknowledgement of the medical expertise of the health professional, as was confirmed by a client participant who explained that she would listen to and highly regard the information provided by the SLP because she does not have that knowledge. Thus, it does not necessarily mean that she played a less active role in the consultation, if she chose to take up a more passive role in consultations because she did not have the medical resources or knowledge to contribute to health decisions.

When client participants were asked about whether or not they were too intimidated to ask for clarifications or admit that they had in fact not understood or remembered clinical information/recommendations, all client participants replied that they had no concerns when wanting to do so. The fact that their SLP was kind, played a significant role in participants' readiness to ask questions and admit to not having understood or remembered clinical information/recommendations. Client participants of FG 2 explained:

**PT4: (interpreter)** She said it depends how is the therapist. If it's somebody nice to them, it can be easy for them to ask the therapist (...)

**PT1: (interpreter)** The same thing, if the therapist is nice, it will be easy for them to ask.

Participants reported that they were not intimidated by these particular SLPs but that they may feel so with some professionals who are less easy to approach. This concurs with findings by Cilliers (2005), who found that clients' experiences of communication of health information and their behaviour and communication in clinics are largely shaped by health professionals' empathy and attention to the client's need for support.

Even though these client participants expressed no concerns over asking for clarifications, the SLP participants have had experiences with clients who have difficulties (a) in making their needs known, (b) in taking charge of information exchange in a consultation and (b) ensuring that they are well equipped to self-manage their health (Zagaria, 2006; Zarcadoolas et al., 2006). Thus, clients need to be provided with client-specific strategies such as the "teach-back" method or telephonic follow-ups, to assist them in information exchange during consultations as well as in managing their health when at home (Osborne, 2008b; Osborne, 2008c).

### ***Effects of mistrust and dissatisfaction with intervention***

According to Paynter et al. (1990), non-compliance frequently results in poor health outcomes for clients, which results in a higher overall dissatisfaction with the delivery of healthcare. One client participant particularly expressed her feelings of mistrust, dissatisfaction and hopelessness as a result of seeing no improvement in her vocal health throughout discussions. She reported not having understood and remembered the initial advice and information that the SLP had given to her and she declined wanting to seek further advice from the SLP or having the financial freedom to attend frequent appointments. She explained:

At least if I can get a job I can do that...to get the money...to come here, and to put the food on the table for my kids and for me.

When investigating this participant's problem further, the researcher discovered that she had been seen for therapy after an operation to her vocal cords, after which it was revealed that she was using false vocal fold adduction to generate voice. A better outcome may have resulted if this client had (a) initially understood and remembered these important details about the state of her vocal health and (b) had the funds to travel for attending further appointments and clarifying her disorder. This is an example of when poor health literacy and lack of finances to attend further appointments

reduces a person's self-efficacy for preventive care practices and disease self-management as well as compliance to treatment regimes (Bandura, 2002; Tattersall et al., 1994).

When clients genuinely mistrust health professionals' advice, little can be done to further assist them in their compliance to treatment (Zagaria, 2006). One SLP participant of FG 2 explained:

(...) perhaps even distrust to some extent in clinicians, ahm where they're not quite sure if what you say really will happen, they'll still chance it, I find.

On the other hand, where there is lack of finance and dissatisfaction in addition to large amounts of information to be processed and recalled at a later stage, there is the need for a strategy that allows clients to review important information and ask for assistance (at low cost) whenever they are in need. The above is in support of a statement by Ley (1982), who affirmed that clients who (a) are satisfied with the medical care they received, (b) understand and (c) recall the medical advice which was provided to them, are more likely to comply with clinical recommendations.

On a different note, one client participant of FG 1 showed great interest in the offerings of SLPs of different ethnicity. She explained:

When they give information, I listen because I don't know this information. For instance the speech therapist (not audible) we don't have those people like, its few in us blacks so when I come to speech therapy, I only see speech therapists in the whites, now I was interested and now I was like listening.

This is one case that is contrary to what was learnt in the literature review where it was gathered that South Africans are generally more suspicious of practitioners from different ethnic backgrounds, who follow traditionally western methods of practice (Madding, 2000; Marfo, 1993). Differences in ethnic backgrounds and medical approaches are thus not always a reason for why clients may mistrust health professionals' advice.

### ***Differences in clients' and health professionals' priorities***

Another important issue that further supports earlier research findings on compliance (Kagee, 2004; Portone et al., 2006) is clients' actual priorities and how these would impact on adherence to treatment regimes. With regards to priorities of caregivers, one SLP participant explained that for example when a child is diagnosed with a syndrome (e.g. Down Syndrome) and the associated difficulties are explained (i.e. feeding, language and physical development); the caregiver will remember and focus on what are immediate concerns (e.g. learning to walk rather than speech and language development). Another example from voice therapy was provided where clients are

frequently required to make life-style changes which might initially make them reluctant to adhere to advice. One SLP participant of FG 2 explained:

I find that a lot with my voice patients. They've got to the personality type that talk a lot and you're telling them; try to talk less. It is impossible. They're not going to be able to do that. Or you tell them, don't smoke and they're smoking two packs a day. (...) I think when it comes to lifestyle changes, people are... you have a bit of adversity I think (...) Or if it's a lifestyle change, that's going to be permanent, they start thinking; hmm I don't think I'm going to do this...(..)

Rosenstock (2005) explained that when a client believes that a given recommendation will be effective in managing their disease or disorder, but at the same time sees that recommendation as being inconvenient, costly, unpleasant, painful or disturbing, they will be less enthusiastic to comply with treatment regimes. Thus, if the readiness to act on health advice is high and the negative aspects of that recommendation are seen as relatively weak, adherence to that advice is more likely. However, if the potential negative aspects of recommendations are seen as strong and the readiness to act on health advice is low, clients may be less likely to act on certain health advice. One client participant provided an example of this when she explained that she attempted to adhere to clinical recommendations on how to preserve her voice, but when these recommendations required a drastic change in her behaviour, time was required to adjust to that advice.

SLP participants of FG 2 further explained that differences in clients' and SLPs' priorities and the degree of importance that clients may attach to whatever health advice professionals view as being important, will determine compliance or non-compliance:

**R:** Ok. So that's basically, they're much more...

**PT5:** Compliant when they perceive the problem as being problem, but when they've been referred by somebody else and they don't really think there's something wrong...often speech and language development is last on their list of priorities (...)

**PT4:** I think our patients' perceived priorities and our perceived priorities for the patient are very mismatched, because in our minds, their communication problem or their swallowing problem should be right up there, and in their lives it's probably not as high up as we would like it to be and I think as a result of that there's a lot of communication problems between the therapist and the patient (...)

In cases like these, where clients' priorities do not match those of the SLP, they could be regarded as non-compliant (Fitzner & Fielding, 1994; Flocke & Stange, 2004). Two SLP participants of FG 1 demonstrated how much less of a priority Speech-Language Pathology services could be for some clients when they told the story of a homeless man:

**PT 1:** I mean for example we had a man today that we saw, who is homeless. He sleeps on the streets. His biggest worry today was where is he going to sleep tonight; can we please give him a letter to the shelter because they won't let him sleep there because he has TB. He was so worried about that and when we wanted to book him in, he didn't want to at first because it was...

**PT 2:** And all he wanted was a shower.

It appears that when a client comes from a very disadvantaged background, speech therapy and other health interventions may well be of lower priority. This may be attributed to the fact that these clients typically spend all their mental energy on the elements of everyday survival (Bradshaw & Steyn, 2001; Kagee, 2004; United Nations Development Programme, 2006). Kagee (2004) emphasised that poverty is likely to affect adherence, as money to pay for medication or consultations may need to be directed elsewhere. Funds for travel may be inaccessible and the competing demands of work and family life as well as the stresses associated with poverty and difficult life circumstances, may contribute to the lack of acknowledgement of the importance of complying with treatment regimes (Kagee, 2004). Another example of such a client was a client participant with a voice problem who cited financial difficulties which forced her to spend what little she had on food and medication rather than on another appointment with the SLP. Some clients might prefer a "quick fix" as opposed to long-term complex speech therapy and recommendations for which they need money, time and mental energy. This is partly supported by Doak, Doak and Root (1996) who found that clients with low health literacy skills are often most interested in information which resolves their immediate health problems rather than following advice that is long-term. Alternatively, it should be noted that when there is compliance, it may significantly reduce the need for ongoing or long-term interventions and where applicable, this needs to be explained to clients.

The theory that a low socioeconomic background influences the relative priority of Speech-Language Pathology interventions in some clients is not always the case. One SLP participant of FG 1 explained that:

(...) they live in a shack with no electricity and no running water and they're wonderful parents and they follow through with your advice so well, and then you get the other ones that don't.

This concurs with statements by Baker et al. (1998) who emphasised that socioeconomic backgrounds are not always indicative of a client's level of compliance. The above also indicates how important it is for health professionals not to judge clients' potential assertiveness and willingness to participate in therapy on accounts of their socioeconomic background. Rather, the

presence (or absence) of other very important personal characteristics play a role in all clients' adherence or non-compliance to recommendations; namely motivation and insight.

### **3.1.3. Client-specific factors**

#### **Personal factors**

##### ***Level of motivation and insight***

SLP participants of FG 2 first mentioned motivation and linked it with clients' priorities and non-compliance when they explained that the interest in attending and following recommendations might be influenced by the motivation to make a specific health problem a priority. If motivation to address a particular health problem is not a priority, clients might be less motivated to comply with recommendations (McDonald et al., 2002). SLP participants of FG 2 realised motivation to be an element in the success of treatment when they explained how they would proceed the same way and provide the same materials to all clients when addressing a particular disorder, but that the outcomes were always dependant on the client. One client participant of FG 1 described the importance of her motivation to adhere to treatment when she explained:

Me for myself, like the other people, like before I came for the operation said; no don't do it. But I told myself; I'm going to do it because I want to get better. The other thing that's better, is to tell yourself ; I'm going to try everything to make myself better.

Another client participant continued to explain that it all depends on the person themselves to play a role in their own healthcare. Clients' perceived importance of clinical information was also highlighted by Richards and Sayward (2006), who stated that a client's motivation is a characteristic without which any strategy, recommendation or treatment regimen will be unsuccessful. Thus, it is important for SLPs to (a) be aware of the issue of a lack in motivation, (b) address this issue when it is a factor in a client's compliance, and (c) provide them with strategies to improve their motivation.

This issue of insight was first mentioned by SLP participants in FG 1 when they stated that the problem of low client health literacy and recall/memory is more than just clients not understanding or remembering their diagnosis. It generally is low insight which impacts clients' understanding and no matter how much effort the SLP makes, insight is a factor which would ultimately affect a client's compliance with treatment. Insight is defined as having the "capacity to gain an accurate and intuitive understanding of something" (Compact Oxford English Dictionary, 2000, p.578). This

prerequisite characteristic was mentioned frequently in the literature review by Fagan et al. (2002) and Moon et al. (1998), who stated that behavioural change and adherence to medical advice can only occur through the application of diagnostic insight and understanding of new knowledge.

Along the same vein, when discussing *client-specific* strategies for providing information and the importance of that for their eventual compliance to recommendations, SLP participants of FG 1 replied that even when client-specific information and assistive strategies are provided; motivation, insight, level of education, priorities, anxiety and low general understanding of health will have an influence on whether or not these strategies will be successful. One SLP participant of FG 1 stated:

**PT 2:** Ja, low insight for me is the biggest thing, you can get by the fact that they can't read, because if they've got insight, boy they remember things...

**R:** Ok so if they don't have insight and motivation, do you think...

**PT 2:** Nothing is going to work.

This is an important finding for any clinical situation and when providing clients with opportunities to manage their own health. SLP participants also emphasised that this is true whether clients come from a high socioeconomic background or not. This finding concurs with Baker et al. (1998) and Williams et al. (1998) who found that regardless of socioeconomic status, clients with limited health literacy skills and insight have less success in treatment.

### ***Sense of role, responsibility and expectations in healthcare***

Clients need to understand that they have a role to claim in their (or their child's) healthcare (Fitzner & Fielding, 1994; Flocke & Stange, 2004; Marfo, 1993). In addition to motivation and insight, SLP participants reported that some clients do not understand that they have a role to play in their (or their child's) healthcare. However, SLP participants highlighted that it is important to consider that a lot is expected of clients when they need to follow and understand foreign treatment concepts (e.g. certain feeding techniques or the concept of the suck-swallow-breath pattern in infants). In the literature review, it was noted that there is an apparent level of "over-expectation" from professionals, regarding clients' understanding and retention of health information as well as claiming their role in the treatment process (Zagaria, 2006). One SLP participant of FG 2 explained:

(...) But especially in the advice that's given, it's just, it's very hard. It's hard stuff that we often expect from the patients to do.

Once more SLP participants agreed that this is true especially when working with voice disorders where the causes for clients' disorders are habits which have been developed over many years. One

SLP participant of FG 2 further realised that at times, too much is expected of clients in terms of recall, especially in the context of public hospitals. She explained:

You sometimes get that before the session is finished. One of the problems is that the client got up three o'clock this morning to get here, so you're not expecting them to have a great memory. Then they saw two doctors before they saw you. They sit for three hours at the chemist after this. They get home ten o'clock the night...

This provides an interesting perspective into what some clients experience when they come to the hospital. There is no doubt that these circumstances would have an adverse impact on clients' abilities to understand and recall clinical information (Fitzner & Fielding, 1994; Flocke & Stange, 2004; Ley, 1979) especially if no assistive strategy is provided to them. SLP participants reported that no matter how cautious professionals are, they cannot rule out misunderstandings in clients but they ultimately realised the importance of providing a strategy that would allow for repetition and review of information to assist in adequate understanding and recall in order to support clients in realising their responsibilities and giving them a chance to take up an active role in their (or their child's) treatment.

### *Effects of emotional variables in clients*

During consultations there are great amounts of information to be processed in the presence of confounding variables such as stress, anxiety and an intimidating clinical environment (Fitzner & Fielding, 1994; Flocke & Stange, 2004). SLP participants of FG 1 agreed that when clients are anxious while they have to learn and understand how to manage their own (or their child's) health, they may absorb less of that information. One client participant of FG 2 confirmed this when she stated:

**Interpreter:** she was shocked when she saw her baby, so she was shocked and she couldn't remember just because she was in shock.

A SLP participant of FG 2 further explained:

I think the emotional component also plays a big part. But in our medical, academic world, we don't factor that in at all. I think a lot of the information that parents get...if they are in an emotional state while they are getting that information, it might not go in as well and they might not remember it as well. (...) But we don't have time, we really don't have time to wait for a client to first be in an ideal emotional state, because there are ten clients waiting for us ... to see them next and it's really unfortunate because if I was the client, I would be upset with such a diagnosis and I would want the doctor to spend enough time with me. It's really unfortunate.

SLP participants showed that they are able to unreservedly empathise with clients. SLPs knew from their own experiences how a successful consultation should be held and what was needed for proper understanding and recall to take place during and after the consultations. However, these therapists are faced with obstacles (e.g. clients' anxiety, time constraints, excessive workloads) when practicing their profession and as a result they may have difficulties in developing new or more efficient and effective strategies.

### **Factors related to health information exchange and related variables**

#### ***Clients adhere to what they think works best***

During further discussions with client and SLP participants, it emerged that low health literacy may sometimes lead clients to proceed with what they initially considered to be appropriate. Clients might be too overwhelmed by vast amounts of “new” information on how to care for themselves or their child. SLP participants of FG 2 explained:

**PT1:** (...) I suppose a lot of parents feel that they know best, they know their child best...ahm and you know if you say the child can only have liquids when they know they could eat solids before they think to themselves; that doesn't make sense, we'll just do it this way. Ahm so definitely not understanding the full consequences (...)

**PT2:** Ahm, I think the family also plays a big role,... ahm, the granny brought up seven children and she feels that she knows how to handle it ahm (...) They try things and if it works once they almost believe that it will work again. So even if you tell them; only try thickened feeds and they don't see the child coughing or going blue on liquids they will keep on trying because they don't really believe that this is it. This is how it's going to be for a while.

These findings further add to research on consequences of low health literacy and recall in management of clients (Arias, 2006; Bandura, 2002; Kessels, 2003; Ley, 1979) and provides insight into clients' coping strategies in the absence of adequate health literacy and recall skills. This further concurs with findings by Donovan (1995), who emphasised that ultimately clients make their own decisions about treatments based on personal circumstances, and the information available to them. Thus, when in doubt after not having understood or remembered information or received a strategy to review important information and ask for assistance, they will proceed with what they think is most accommodating to their (or their child's) immediate health needs (even if it might not be the best approach).

***Low health literacy skills and recall affect the success/duration of treatment regimes resulting in various consequences***

When asked whether or not clients' difficulties in recall and understanding of clinical information is detrimental to the success and duration of their treatment, SLP participants of FG 1 agreed and one participant added:

...definitely if your question is if they remembered and understood it, does the treatment go faster then yes, I mean I would say so. Otherwise you might as well, you're starting from the beginning every time.

According to these SLPs, clients' difficulties in understanding and recalling clinical information can have serious consequences. SLP participants of FG 2 explained that in cases where clients had difficulties in recall and understanding of clinical information:

**PT1:** They just don't come back.

**PT2:** I just wanted to say, if they do not understand, they don't come back.

**PT4:** Hmm...they often don't.

**PT1:** And then you might see them two years later in the ward with another pathology (...)

When some clients do not return for continuation of therapy, their initial difficulties might lead to greater problems for which they need to return to the hospital at a later stage. When asked whether these participants felt that this added to their workload, they replied:

**PT1:** It does! It does, because the ENT doctor will refer them again and you can tell them; I saw this patient six months ago and this is what happened. So it does happen a lot...

**PT2:** I think also a thing is, if they don't understand what you're saying ... (...) so they're trying something but it's not really the right thing, you sit the second time so much longer because not only are you trying to explain the right thing, you also try to explain to them why they can't do what they've been doing...

Another example of the consequences of clients' difficulties in recall and understanding with swallowing or feeding difficulties was provided by a SLP participant of FG 2 when she explained:

With my adult dysphagia clients I find it lightens the workload when they don't understand...(…) because either they do something horribly wrong at home and it goes wrong and they... pass away...or they come back into hospital with massive complications and then the doctor will say; you've had your trial of speech therapy, you can't do those techniques at home because they don't work for you so now it's peg...So in a horrible way it lightens the workload for my adult dysphagics.

This example is contradictory to the what SLP participants of FG 2 explained earlier where they stated that it was easier for clients to remember and adhere to recommendations for dysphagia because they are so few. The consequences of non-compliance with dysphagia management are that

clients either pass away or are referred for a surgery (Chadwick et al., 2002; Cherney, 1994). This is a serious consequence which needs to be avoided through adequate strategies to assist these clients in managing their own health problems. SLP participants affirmed that even though clients are provided with strategies such as written recommendations, some will still return without having followed any of the advice or being able to recall certain aspects of it. Besides additional health costs to the clients as a result of having no success in treatment (Rao, 2007), other professionals might think that Speech-Language Pathology services are of no use because they see no progress in clients. SLPs explained that clients lose hope when there is no success in treatment and these SLPs become frustrated and sometimes need to spend more time with clients to correct what was misunderstood or not remembered which further adds to their workloads (Arias, 2006; Rao, 2007; Stone, 1979). This provides another reason to develop strategies that provide clients with an opportunity to review information and a chance for regular (low-cost) contact between a client and their SLP to improve health literacy and recall along the entire treatment process.

### ***The issue of literacy skills***

SLP participants made interesting statements, when it came to discussing the influence of clients' literacy skills on their understanding and recall of clinical information. One SLP participant in FG 1 explained that she had not come across many clients who could not read and when she did; there was someone in the family who could assist. However, these participants did not know how clients can go to great lengths to cover up the fact that they have low or no literacy skills (Moon et al., 1998; Parikh et al., 1996). Later in the discussion SLP participants of FG 1 challenged their earlier statement when they explained that after considering the case of the homeless man for example, one cannot always rely on a client's or their family members' reading skills to deal with added written clinical information and advice.

SLP participants in FG 2 further explained that for example when a child was diagnosed with swallowing and feeding difficulties, it was inappropriate to only provide a package with reading materials which are not regulated to clients' levels of literacy because the consequences can be severe (Chadwick et al., 2002; Cherney, 1994) when these materials are misunderstood or misused. SLPs of FG 2 frequently come across clients from rural areas who cannot read and also do not have a family member with them, who can assist. Thus, it is not always appropriate to provide written information to clients who have limited or no literacy skills and expect them to rely on these when reviewing important information and advice or conveying recommendations to other family members. It would be more appropriate for clients to have a strategy which gives them the power to

take charge of recalling, processing and applying clinical information rather than having to always rely on others to act as mediators between them and the written details to information about their treatment.

SLP participants of FG 2 added that understanding and recall of clinical information is not only an issue with clients who have low literacy skills but those who have good literacy skills too. These SLPs found that clients sometimes misunderstand or lose the written materials provided. This concurs with findings by Plimpton and Root (1994) who found that much of the literature provided by healthcare professionals goes unread even by able readers as they do not have the time and high level of interest to decipher them. SLP participants added that the only difference between clients with low socioeconomic status and literacy skills and clients with relatively high socioeconomic backgrounds is that the latter typically have tools such as the internet and libraries more readily available for them to improve their health literacy skills. Clients who are less fortunate have to rely solely on the information that SLPs and other health professionals provide. Once more, research is needed to investigate how to make it more convenient and cost-effective for clients who are less fortunate to review and discuss information long after they have first consulted their SLP.

***Consequences of non-compliance and recommendations are disregarded, misunderstood, forgotten or too difficult to adhere to***

It was confirmed by SLP participants that even though it was easier to revise information and remind clients who are stationed in medical wards about important treatment information, the issue of low understanding and recall of that information and consequences of non-compliance is prevalent in both out-patients and in-patients. SLP participants of FG 2 commenced this debate when they explained that some clients with dysphagia either forget or ignore recommendations especially when they are surrounded by family in the hospital or in their home environment who often do not understand or support health professionals' recommendations. Clients' non-compliance in these cases was attributed to difficulties in recall/memory, possible disregard of recommendations and difficulties in understanding/acknowledging the possible consequences of non-compliance. However, a contradictory example of the above (though not related to swallowing disorders) was provided by a client participant who explained that when she received new information about how her voice functions and how to preserve it, she felt that it was important to understand and follow clinical information or recommendations provided by the SLP.

Nonetheless, SLP participants were unsure if most clients' non-compliance was as a result of possible disregard of recommendations or little understanding and recall of consequences of non-compliance. They thought that some clients might genuinely have difficulties in understanding or acknowledging the possible consequences of non-compliance. Others might also just disregard recommendations or advice. This could be as a result of attaching less priority to the care of their disorder or it might be as a result of not being adequately supported by the people in their immediate environment. Some clients might also be emotionally overwhelmed by their disorder and the clinical environment and thus take up less of the advice that is given at the time (Fitzner & Fielding, 1994; Flocke & Stange; 2004).

One client participant of FG 2 explained that what was most difficult for her to understand was the rationale behind the advice for feeding her child. She explained:

**Interpreter:** ... she said the therapist told her how to feed her baby so she must feed her baby after three hours ... She couldn't understand for feeding her baby after three hours. That was very difficult for her to understand. (...) Because the baby always keep on crying between that three hours so she was worried about her baby. That is why she have to brake that three hours and feed the baby. So that was very difficult to understand.

The rationales behind treatments are often the most important parts of information because when a client does not understand or remember why they are following recommendations, they might see less use in following them (Kagee, 2004). Furthermore, some client participants disagreed that they felt comfortable in following what the SLP recommended once they were at home because they had difficulties in understanding, remembering and organising the vast amounts of information provided by various professionals. This concurs with Ley (1979) who found that one reason why clients may forget recommendations for their rehabilitation in a relaxed home environment is because this particular advice is given in a stressful clinical environment. The fact that clients see many different health professionals at one visit to the clinic further complicates the process of organising information, knowing when to ask for clarifications and using each professional's advice to appropriately manage their (or their child's) health.

When asked which professionals' information was easiest to remember and follow at home, client participants of FG 2 replied that even though they could remember some of the SLPs advice, it was easier to follow the doctor's advice once they were at home. It was difficult for these participants to identify an exact reason. One reason may be that the advice and treatment provided by SLPs is typically more abstract, complex, descriptive and long-term (Enderby & Emerson, 1996) than the

information provided by medical doctors whose advice can be more short-term and focuses on immediate physiological needs (Wilson, McDonald, Hayes & Cooney, 1992). This reason was supported by SLP participants of FG 1, who found that SLP interventions are more descriptive and require the retention of a great deal of information.

Another factor which may play a role here is that clients may only consider medication to be real treatment rather than behavioural regimes (Kagee, 2004) such as Speech-Language Pathology interventions. Some client participants reported that they struggled to implement some of the SLP's recommendations as a result of their complexity. When asked what they do when they struggle to remember recommendations, client participants of FG 2 replied:

**PT4 and PT3: (interpreter)** They end up not doing it, what they told them because they don't remember.

**PT1 and PT2: (interpreter)** She also don't do it, she just do what she remembers.

When asked how that makes them feel, participants responded:

**PT4 and PT3: (interpreter)** They are becoming worried because they will just stare at the baby because they don't know what to do so they are becoming unhappy because they don't know what to do but they try to remember but they can't remember.

**PT1: (interpreter)** She just sits and think and think and think and then she just leaves it like that. Actually she is becoming worried also because she don't know what to do.

Not following recommendations, makes them feel anxious and despondent especially when having to care for a child. These consequences further concur with research findings on the results of low health literacy and recall skills (Bandura, 2002; Kessels, 2003; Ley, 1979).

Even though many client participants had difficulties in adhering to recommendations, some client participants explained that they had no difficulty in understanding or remembering the information that was provided to them. Having said that, SLP participants of FG 1 provided another interesting perspective to this when they explained that regardless of whether or not clients understand or remember clinical information, there is also a chance that they think they fully understood and are correctly following recommendations when in fact they are not. One SLP participant of FG 1 explained:

... because if they forget or something like that I mean... they might not know that they don't know.

Clients may be unaware of this and as a result may become frustrated because they do not see any success in following recommendations (Ley, 1982). They might become dissatisfied or be regarded as non-compliant because SLPs do not see any progress. The above provides additional insight into

the complexities of information exchange in the clinical setting and that regardless of health literacy and recall skills; the chances of misunderstandings occurring are likely and when not paid attention to could result in less success in treatment.

***Lack of access to, and awareness of general healthcare and Speech-Language Pathology services***

During discussions with SLPs, it appeared that there were two more factors which played a role in client adherence and readiness to comply with recommendations. These were (a) knowledge/awareness of health and the necessary services and (b) apparent differences in clients' following of one health professional's advice over another. For example, one SLP participant of FG 2 made a comment about clients not being bothered to follow her advice and rather following what the doctor had advised. These SLPs ascribed this to clients' lack of awareness of general health and various (other and Speech-Language Pathology) services as well as the fact that effects/consequences of Speech-Language Pathology disorders only appear in the long-term. Once more, differences in priorities may also lead some clients to follow the advice of one health professional's advice over another (Donovan, 1995). For example, one SLP participant in FG 2 explained:

I also think it's important, what's important for the parent. If it's in the community, it's important for them that the child can walk before they can read a book. They need to walk they need to help themselves, pick up things. So when they can do that, they'll start worrying; oh my child's not coping at school or not reading or writing or things like that. But the immediate need is that the child needs to walk and be able to participate in the home environment and if they can't do that, that's what they need to address first.

Thus, a caregiver might prioritise adhering to a Physiotherapist's recommendations over a SLP's advice.

SLP participants further explained that they have tried to raise awareness about Speech-Language Pathology services during awareness weeks at the hospital, but that people seem to be less interested when it is not something which addresses their immediate health problems. SLP participants attributed the lack of awareness to under-representation of the profession at primary and community level, lack of knowledge about services in clinical staff, lack in promotion of services and clients' difficulties to access services.

### **3.1.4. Interpersonal factors**

#### ***The presence of support structures***

SLP participants of FG 2 highlighted that compliance and support complement each other and that when an individual does not have the support from the family or a health professional, their compliance will be negatively affected. One client participant of FG 1 agreed with this when he stated that it was very important to have someone who stands by him and motivates him. He continued to affirm that it is his wife who also has an important role to play in his well-being, which shows the significance of family support in a client's motivation to comply with treatment. A different client participant explained that if her neighbour, who was also suffering from voice problems, had been able to attend the consultations with her, they could have supported each other on their road to recovery. Another client participant further wished she had had the support from people around her to follow her treatment regimen. The importance of social support in clients' ability to successfully adhere to treatment regimes is not to be underestimated. Without support from the people around them, strategies to further assist clients in their adherence to treatment guidelines will be insufficient (Ciechanowski et al., 2001; Kagee, 2004; Roberts 2002).

#### ***Loss of carry-over of information between caregivers***

Another important observation is that of loss of carry-over of information between caregivers. Grandparents play a central role in the care-giving of their grandchildren when both parents are working full-time or in remote areas of the country. This is commonly the case in rural areas where husbands work in mines and wives commute to the cities in order to work as domestic workers (Mdladlana, 2001; Tolan, n.d.). However, these SLPs explained that when the child is ill it is the mother or the father who takes the child to healthcare facilities. It is between these three parties that information can get lost which calls for a strategy where information can be accessible to grandparents and significant others whenever it is needed.

### **3.1.5. Clinical variables**

#### ***Differences between disorders and compliance with treatment regimes***

During further focus group discussions, it appeared that there are definite differences between disorders, clients' abilities to recall information and their ultimate compliance with treatment. Furthermore, it became clear that SLPs try to accommodate for difficulties in client information

recall but are faced with many obstacles. SLP participants of FG 2 explained that when they manage complex disorders such as dysphagia, they provide most information in written form for those clients to take home. However, it appears that these materials are frequently lost. They also highlighted differences between advice provided to clients with dysphagia and voice disorders. Advice given to clients with dysphagia is usually one or two techniques and they typically show immediate outcomes whereas clients with voice disorders are given a range of recommendations for which the outcomes are only seen after a longer period of time. SLP participants of FG 1 added that clients with dysphagia know that recall, understanding and compliance is crucial for their survival. On the other hand, these SLPs found that when it comes to caregivers of children, there frequently is non-compliance with advice. A possible reason for this was cited as the fact that the caregiver does not physically feel the consequences of when the child is misfed. Depending on types of disorders, it is understandable that the amount of clinical information and recommendations that need to be understood and recalled will vary, causing some clients to be able to remember more or less than others which ultimately may affect compliance and treatment outcomes. Here, insight is provided into what SLPs need to look out for when it comes to health literacy, recall and other variables to compliance in different disorders.

***The issue of language differences (bilingualism and lack of trained interpreters)***

In addition to all the issues that were mentioned around health literacy and client recall/memory of clinical information, SLP participants of FG 1 raised one last issue, namely that of interpreters. They explained that most of the time interpreters are not available and when they are, they are untrained. Interpreting is not just a simple translation from one language into another (Bunning, 2004). It involves knowledge of a client's condition, circumstances, culture and ethnicity on the part of the interpreter and it demands skilful use of non-verbal and verbal skills by the SLP. According to Penn (2007), the majority of health interactions in South Africa are mediated by a third party and more than 80 % of these interactions between clients, a third party and health professionals take place across linguistic and cultural barriers. Little is known about this process even though the majority of health professionals, with the exception of the nursing profession, cannot speak any of the indigenous South African languages (Drennan, 1998). English and Afrikaans are most prevalent as health professionals' mode of communication. However, in many parts of the country, clients that are seen in public health-care facilities have little or no English/Afrikaans language or literacy skills (Drennan & Swartz, 2002; Penn, 2007).

The availability of trained interpreters is still scarce and often health professionals resort to family members or nurses, general assistants, cleaners or fellow clients for assistance in interpreting at healthcare institutions (Penn, 2007; Roberts, 1997). However, this method of information exchange has the potential to result in misinterpretations which can be frustrating for health professionals as well as clients as they are being forced to interact through a third party. Where nurses, general assistants and cleaners are used, the system at the hospital is disrupted and using these mediators carries ethical consequences (Penn, 2007). Even though there might be many hurdles that have to be overcome initially, the presence of an interpreter during consultations with non-English speaking clients is essential. The interpreting process will ultimately improve with practice and its efficiency will depend on skills and co-operation of a well-balanced team and respect for each member in the mediation process (Penn, 2007).

## **Conclusion**

When discussing issues around clients' difficulties in understanding and remembering clinical recommendations, participants had much to say and often the reasons for non-compliance were not only poor understanding or recall. SLP participants explained that if clients have understood, processed and remembered most clinical information and efforts are made to address barriers to compliance, clients are empowered and equipped to take their (or their child's) health into their own hands. SLPs also thought that this would make clients more likely to follow-through with therapy.

During focus groups conducted with SLPs it was noticed that these SLPs had a good understanding about factors which play a role in clients' understanding and memory of clinical information as well as their compliance with treatment regimes. However, these SLPs seemed to be at a loss for ideas/strategies/interventions to improve on these issues (which they have to deal with on a daily basis). The issues that were raised call for an investigation into strategies that (a) support clients' ability to review the vast amounts of clinical information/recommendations that are provided to them and (b) encourage and improve the access to communication with health professionals so that when in need, clients can clarify information, ask questions and receive immediate feedback at any time post-consultation. Additional materials are needed to ensure that once clients have left the clinical setting, the information they received is clear, accurate, complete and available for problem solving, review and discussion with other health professionals and family members (Kessels, 2003). Parker et al. (2003) suggested that a health strategy needed to be developed which could address disadvantaged groups. At the same time it would need to be linguistically and culturally sensitive

which is where the adapted Triple Constraints Model becomes an important concept. It is clear from the discussions above that if this is not at least attempted, clients, SLPs as well as the profession in general will continue to suffer serious consequences.

### **3.2. SLPs' and clients' suggestions and views on strategies to maximise health literacy and client recall/memory**

The aim of this section was to merge ideas, suggestions and views from all participants in phase 1 to decide on strategies to be trialled in phase 2 of the study. The sub-themes to this section were divided into (a) SLPs strategies and what clients think of them, and (b) SLPs and clients' views on strategies proposed by the researcher, subsequent to which strategies were chosen to be trialled in phase 2 of the study. SLP focus groups were conducted first and client focus groups were conducted subsequently. Therefore no views of SLPs on clients' suggestions could be collected.

SLP participants in this study knew about the importance of strategies to improve recall of information as a result of their own experiences with the healthcare system. SLP participants in FG 2 explained that when they go to the doctor they themselves need some materials to be able to review advice and recommendations. One SLP participant for example realised:

(...) Because I don't remember if a doctor just talks, I'll remember points because it's just too much and you're trying to understand the complexity of something so you might forget the points.

Another SLP participant concluded:

(...) and I think we're expecting a lot of clients if we don't provide them with something (a strategy) like that.

Besides the importance of strategies to assist in health literacy and recall, these excerpts yet again illustrate that recall and health literacy are not linked to education or socioeconomic background. A strategy to allow for review and recall of health information is needed by almost any person who consults a health professional. When asked to share strategies that are currently used by SLPs to ensure clients understood and remembered clinical information and recommendations with the group, it became clear that rather than having a standard method, the strategies that SLPs utilised commonly depended on a range of variables.

### 3.2.1. SLPs' strategies and what clients think of them

The following Table provides a summary of nine strategies that are typically used by these SLPs to improve health literacy and client recall/memory of information. They are presented in order of most to least used, subsequent to which a discussion of each strategy is presented.

Table 7. Summary of strategies typically used by SLPs to improve health literacy and client recall/memory of clinical information

<b>Strategies typically used by SLPs to improve health literacy and information recall</b>		
<b>Strategy</b>	<b>SLP opinion</b>	<b>Client opinion</b>
<b>Written materials</b>	<p>Most appropriate for:</p> <ul style="list-style-type: none"> <li>- voice disorders</li> <li>- dysphagia</li> <li>- laryngectomies</li> </ul> <p>( Format: simple handouts with background information, advice and techniques)</p>	<p>Helpful for:</p> <ul style="list-style-type: none"> <li>- recall of general information</li> <li>- understanding treatment techniques</li> <li>- correct implementation of recommended techniques.</li> </ul> <p>Even though most participants did not have any problems with written information, some preferred practical demonstrations.</p>
<b>Detailed explanations, demonstrations and practice during sessions</b>	<p>Enables clients to comply when they:</p> <ul style="list-style-type: none"> <li>- understand their own role in their management</li> <li>- understand each health professional's role</li> </ul> <p>Clients want to know that they can take charge of their own healthcare and when explaining their management holistically, they can understand where their role becomes important.</p>	<p>Unrushed demonstrations of therapy techniques and practice in sessions helped to:</p> <ul style="list-style-type: none"> <li>- make it much easier to follow through with recommendations</li> <li>- view demonstrations and practice techniques rather than just receiving written materials</li> <li>- recall techniques, having tried them with immediate positive outcomes in session</li> <li>- make it easier to understand and apply advice than from written materials</li> </ul>

<p><b>Repetition/ revision of clinical information during sessions and post-consultations</b></p>	<ul style="list-style-type: none"> <li>- Interactive training (demonstration – repetition – hands on practice etc) is a reasonable strategy for clients to understand rationales behind techniques or advice.</li> <li>- Allows clients to understand, revise and remember goals and advantages of therapy making it is easier for them to comply.</li> </ul>	<ul style="list-style-type: none"> <li>- Repeated information is helpful.</li> <li>- It is important to know who one can contact for help.</li> <li>- Information repeated during a follow-up call is re-assuring and decreases anxiety.</li> </ul>
<p><b>Illustrations</b></p>	<ul style="list-style-type: none"> <li>- Most appropriate for use with clients with voice disorders/laryngectomies for explanation of physiology of anatomical structures.</li> </ul>	<ul style="list-style-type: none"> <li>- Helpful to learn about/understand anatomy and physiology of the voice.</li> <li>- Client participants who had not experienced the use of this medium by SLPs said they would have found it helpful to have illustrations: to understand disorder and to be reminded of exercises/techniques.</li> </ul>
<p><b>Support from family members and SLPs during and after consultations</b></p>	<ul style="list-style-type: none"> <li>- Important for EVERYONE involved with client to be informed &amp; realise their role in the treatment regimen.</li> <li>- Family members can then also serve as sources for information clarification and review of what was discussed during consultations.</li> <li>-Important when managing children (e.g. with dysphagia) because when the mother gets distracted by the child, who is crying for example, second person can listen, ask objective questions &amp; note important information.</li> <li>-Important for upholding a caregiver's self-confidence (i.e. there is someone who will praise them and encourage them to follow recommendations correctly).</li> <li>-Clients may be much more comfortable when having someone from their neighbourhood with them, to assist them and share knowledge once they are at home.</li> </ul>	<ul style="list-style-type: none"> <li>- All other participants agreed that it would have been of benefit to them if they had had the chance to bring another person with them to consultations so that when they misunderstood or forgot certain details, the other person could assist them.</li> <li>- Especially in the beginning of a treatment regimen, it is important to be supported, motivated and assisted by the SLP.</li> </ul>

<p><b>Telephonic contact</b></p>	<ul style="list-style-type: none"> <li>- Appropriate to use with clients who have voice disorders, dysphagia or laryngectomies, to reinforce advice and techniques and check progress.</li> <li>-When in need, clients can contact SLPs at work or in extreme cases on their mobile phones.</li> <li>-Clients do not typically see telephonic contact as a method to access information and support or provide feedback to their SLP.</li> <li>-Access to telephones can be a problem in rural areas.</li> </ul>	<ul style="list-style-type: none"> <li>-Beneficial when SLPs contacted clients telephonically especially when clients need encouragement and support or are experiencing problems with their treatment programmes.</li> <li>-Participants replied that they only phoned to make appointments even though the SLP had told them to phone when there was a problem.</li> </ul>
<p><b>Fewer goals together with intensive short-term block therapy</b></p>	<ul style="list-style-type: none"> <li>- Keeping goals limited reduces the chance of clients becoming overwhelmed and clients can make time to reach them.</li> <li>- Block therapy (rather than long-term therapy), helps clients to understand and remember where therapy is going and when it is going to end.</li> </ul>	<ul style="list-style-type: none"> <li>- No views on this strategy were identified.</li> </ul>
<p><b>Audio-visual materials</b></p>	<p>Divided SLP opinions included:</p> <ul style="list-style-type: none"> <li>- Videos are useful to show &amp; help clients scheduled for laryngectomies to understand what is entailed in terms of the surgery etc. including lifestyle changes.</li> <li>-Videos are not used – even though their potential usefulness was recognised.</li> <li>- Many clients (&amp; other health professionals) would rather watch audio-visual materials.</li> </ul>	<ul style="list-style-type: none"> <li>- Client participants here did not have experience in the exposure to audio-visual materials during their consultations with SLPs.</li> <li>- Most of them thought that it would have been beneficial for them to view audio-visual materials about the treatment of their disorders to assist in understanding and recalling important information.</li> </ul>

### ***3.2.1.1. Use of written information***

Written materials in the SLP profession typically consist of pamphlets, brochures, posters, information sheets and lists with recommendations when managing voice disorders, laryngectomies, dysphagia or cleft lips and/or palates. These materials usually include general information, advice, techniques and procedures that need to be understood and implemented by a client. These SLPs' preference for providing written materials could be as a result of findings by Stockler et al. (1993),

who found that health professionals preferred to provide clients with a letter with important pointers and recommendations as it was easier to file, store, and copy and it was more appropriate for speedy review and reference.

One client participant received an isiXhosa booklet on the most important aspects that a parent had to know about cleft lip and/or palate. This booklet was briefly discussed in the literature review (Bellardie & Harris, in press). The client participant explained that the booklet assisted her in understanding and remembering important details about her child's birth anomaly and the treatments that were due. However, the researcher had previously accessed that particular booklet and found it to be very detailed with some pictures and a great deal of writing which could make access to these materials difficult for clients whose literacy skills are not sufficient. Furthermore, as was outlined in the literature review, the written materials which are often handed out together with verbal instructions are not always valued or clearly understood in the South African client population (Louw et al., 2006). The comprehension of printed materials depends on the level of readability, interest in the material and health literacy skills (Kahn & Pannbacker, 2000). Thus, because the above variables might have an impact on some clients' success in using written materials effectively, other avenues of information exchange need to be explored.

### ***3.2.1.2. Detailed explanations, demonstrations and practice during sessions***

This method of information exchange was applied by SLPs in both focus groups with most clients regardless of their disorders. It is a reasonable technique that allows clients to become familiar with treatment techniques, their roles in their treatment regimen and they can experience first-hand how the service of each profession is of relevance to the management of their health problem. This technique also satisfies the constant need and importance of clarification of the healthcare system which may be especially important for clients with low health literacy skills so that they can understand, process, organise and ultimately adhere to clinical information provided by various healthcare professionals (Zarcadoolas et al., 2006).

With specific reference to swallowing disorders, it appeared that client participants found it easier to understand and recall recommendations because they are fewer, simple and results are immediately generated. This is one aspect where dysphagia management is distinguished from interventions for other disorders that typically involve vast amounts of information, more complex interventions and results only appear at a later stage (Louw et al., 2006; Sataloff, 2006). The fact that this is what

distinguishes dysphagia from most other disorders was also mentioned by SLP participants in section 3.1.

### ***3.2.1.3. Repetition/revision of clinical information during sessions and post-consultation***

Some SLP participants use the “teach-back” method (Osborne, 2008c) which was first explained in the literature review. Rather than just informing and training clients how to manage their disorder, clients need to have a chance to demonstrate that they have understood their treatment regimen as well as the rationale behind a technique. One SLP participant of FG 2 linked the importance of this strategy to ensuring that clients are satisfied and confident that they have understood and will remember information once they have left the consultation. She explained:

(...) a lot of them, they pay a lot of money to get here. It might not sound a lot to us but for them it's a big sacrifice and you can't send them home if they don't absolutely feel that they got something from the session...and a lot of that is about explaining, explaining, explaining, just reinforcing things all the time.

This satisfies the statements by Rosenstock (2005) who found that information needs to be relevant and provided in a way that upholds clients' confidence in their own abilities and self-efficacy so that they can become more self-efficient and compliant. Having the opportunity to visit the SLP on a regular basis is an ideal method for continuously revising and clarifying clinical information and recommendations. However, it is unfortunately not a possibility for clients who come from remote areas or who do not have the financial means for transport (van Deventer, 2007). Some caregivers did not have an opportunity to have information revised at any point post-consultation. The fact that they had difficulties in understanding and following through with recommendations (as was revealed in section 3.1.) highlights the necessity of a strategy that allows for clinical information to be repeated, revised and clarified at any time post-consultation.

### ***3.2.1.4. Use of illustrations***

During Speech-Language Pathology consultations, various drawings and diagrams are used especially with clients who have voice disorders or who have had a laryngectomy to show the physiology of anatomical structures. Client participants revealed a preference for information being accompanied by illustrations for ease of understanding and reference to clinical information and recommendations. While this is an important strategy to assist clients (especially with low literacy skills) in understanding and remembering spoken instructions, it is important to understand that the recognition and understanding of pictographs requires visual literacy, which must be acquired

separately from reading and written skills. Without visual literacy the message encoded in a pictograph is lost (Houts et al., 2001; Mansoor & Dowse, 2003).

### ***3.2.1.5. Support from family members and SLPs during and after consultations***

During discussions in section 3.1., most SLP participants already realised the effectiveness of having a third party involved in information exchange when consulting with clients and once the client is at home. Here, they explained that someone (i.e. a neighbour or personal friend) who is not directly involved in the care of a client can probably deal with the information that is provided during consultations objectively. SLP participants of FG 2 explained that these agents can understand, process and recall information more readily as they do not have psychological and physical interferences when dealing with information exchange during consultations. Variables, which frequently impact clients' abilities to fully attend to information exchange and management of their disorder (Fitzner & Fielding, 1994; Flocke & Stange, 2004). SLP participants of FG 2 explained:

**PT1:** (...) just you know get someone else in the house who can kind of remind them. I found that also works quite well.

**PT2:** I think, not even (just for) review, but it's also, you have more confidence in yourself if someone comes and says; oh ja that is what the therapist said, that's nice... you're doing it right, because after a week passed you're not sure; is this what she said or demonstrated, am I doing the right thing? So if you have someone to acknowledge that you are doing the right thing...

One client participant of FG 2 also saw the value of this strategy when she explained:

**(Interpreter)** She said, they were reminding each other, another thing, because as they said they were three so if somebody forget another thing the doctor said, so they were reminding each other that is why they were three.

This could also be translated into making use of support groups or parent-to-parent support groups in the community which concurs with findings by Rao (2007) and Bunning (2004) who both emphasised the importance of the involvement of significant other people in the management of a client. The only problem with this method of providing an independent information resource as well as assuring support and reinforcement of clinical information is that clients often do not have the financial means to always travel with a second person. The scarcity of having a second person attend the consultation with them was revealed during discussions with client participants. Only one of each group of participants had the opportunity of having a family member attend the consultation with them. Community support groups would be a reasonable solution. However, these would not be

very efficient when a client needs patient-specific and detailed information and feedback to assist them in their management of a disorder.

Another problem is that when support structures in a client's environment give negative feedback or disagree with what a caregiver or client is doing, this reinforcement might have a negative effect on the client's self-esteem and possible success in following recommendations. Thus, an additional strategy that allows a client to review information independently and take charge of their (or their child's) treatment while having a chance to discuss feedback with their SLP post-consultation to determine if they are making progress in their treatment, is indicated.

### ***3.2.1.6. Receiving and/or initiating telephonic contact***

It appeared that telephonic contact is most frequently used by both SLPs and clients for crisis management. SLP participants of FG 1 explained:

**PT 3:** (...) voice and swallowing I mean we often follow up with phone calls, you know, not long after... (the consultation).

**PT 2:** If they're aphonic, she's lost her voice I say; do you remember what I told? Doesn't remember and I would kind of reinforce the technique on the telephone. Even swallowing we do it yes.

SLP participants of FG 2 added:

**PT 5:** I think ja with laryngectomy patients for example (...) It's like crisis management and it's also quick fix problems whereas language therapy or communication therapy is more long-term... so they just live with it every day and it doesn't become a crisis.

Client participants have had positive experiences with telephonic contact but whether they would actually initiate telephonic contact with the SLP remains uncertain. The financial support to regularly contact a health professional may not be available. Furthermore, some clients may not be used to utilising this medium of communication for review of information and feedback. One SLP participant of FG 2 explained:

I just always found that they basically would phone for another appointment ...but not to ask for advice or to say...I'm having difficulty remembering what you said about the home program or (...). They just sort of when they go off on their ... (was not audible), you don't really hear from them in-between time.

The effect that regular telephonic contact might have is that (a) a chance to review information and problem-solve together with the SLP might assist clients in the progress of their recovery, and (b) SLPs' workloads might actually be lessened because problems are dealt with appropriately, which makes it a more cost-effective strategy. It suggests the need for a strategy that makes it more

attractive and easier for clients to be in telephonic contact with their health professional regardless of whether they only need clarification and reassurance or whether there is a crisis.

### ***3.2.1.7. Fewer goals together with intensive short-term block therapy***

SLP participants explained that keeping goals limited while making use of weekly therapy or block-therapy instead of long-term therapy is one strategy which assists clients in keeping an overview of therapy and knowing that they have sufficient time to achieve goals. It is also of benefit because clients are not overwhelmed by too many readings and information (Leiter, 2004). When asked what SLPs resort to when clients reside in remote locations and do not have the time and financial means to attend weekly therapy, they explained that they would use telephonic contact if it was possible. However, some issues that are related to telephonic contact were mentioned above and thus an *additional* strategy is needed which would allow clients to work on managing their disorder intensively, but in their own time.

### ***3.2.1.8. Use of audio-visual materials***

Sometimes, these SLP participants use of audio-visual materials for information exchange with clients when having to inform clients about disorders or how a procedure will alter their life-styles as in the case of laryngectomies for example. Most SLP participants thought it to be a reasonable strategy for promotion of services and education of disorders covered by SLPs. The interesting point that was made by SLPs was that some clients are generally not as interested in reading as are health professionals with years of academic training behind them. Some clients would rather watch audio-visual materials. The intense focus on multimedia and the major role that it plays in distributing information (Hui Kyong & Keenan, 2006) suggests that it should be recognised and utilised more by SLPs when exchanging information with their clients.

## **Conclusion**

Client participants typically appreciate any strategy used by their SLP. However, they preferred practical demonstrations, personal contact and support as well as a chance for practice, review, repetition and clarification of information and recommendations long after their first consultation with the SLP. SLPs in general have appropriate strategies to maximise clients' information uptake and recall during consultations and post-consultation. Four out of eight strategies are supposed to

ease carry-over of information into clients' everyday environments. These are for example written, illustrative materials or bringing someone with to the consultation. However, these strategies each have their own set of problems. Most of the strategies discussed require clients to have appropriate literacy skills and some are also not always a constant to rely on (e.g. the need for additional travel costs when needing to bring another person to consultations).

It is apparent that little time and attention is spent on assuring that understanding and recall of information is effectively and consistently carried over from the clinical setting into the clients' everyday environment. Furthermore, SLPs have not paid enough attention to improving health literacy and recall/memory of clinical information in clients who (a) reside in rural areas, (b) have low literacy skills or (c) have low socioeconomic backgrounds. Speech-Language Pathology interventions are complex and require an adequate level of insight to understand, process and recall old and new information in order to adhere to treatment regimes. All of the above highlights the need for research into strategies which would serve as sources for information clarification and review and allow regular access to discussion and feedback with a SLP. It is also a matter of assuring treatment efficacy and addressing issues of cost-effectiveness, user-friendliness and cultural appropriateness in strategies of information exchange.

### 3.2.2. SLPs' and clients' views on proposed strategies provided by the researcher

The following section deals with the views of SLPs and clients on three strategies for providing information, namely SMS, reminders and audio-recordings. The SMS feature was introduced in the literature review (section 1.6.). Reminders and audio-recordings were introduced in detail in Appendix B (Table 1). These strategies were based on ideas generated from the literature review and experts of information technology. They were introduced to all focus groups.

#### 3.2.2.1. SMS

SLP participants revealed that they had never considered this medium because of cost implications, accessibility and practicality issues. SLPs agreed that no matter how low/high their socioeconomic backgrounds, most clients have mobile phones or have access to a family member's mobile phone. However, they do not necessarily always have airtime. Other concerns were the presence of low literacy skills, functional status and dexterity. One SLP participant of FG 2 explained:

...well literacy I think is an issue, because...ahm and a lot of the patients we see are older, so they're quite anti-technology on the whole anyway. (...) I mean it's going to have to depend on how high functioning he is.

With regards to the concern about clients being 'anti-technology'; the opposite was mentioned in an interview with Braun (as cited in DeBevois, 2006) on telerehabilitation (live conversations with health professionals and videos via the internet). He stated that clients appreciate access to healthcare and they seem to be motivated by the use of technology. He further emphasised that even those clients who have limited technology experience, "technophobia" (DeBevois, 2006, p. 3) does not play a major role when they report on satisfaction with the way that treatment is provided. In addition, clients were more pleased with treatments and more willing to complete programmes at home when they had regular access to a SLP (DeBevois, 2006).

SLPs also thought SMSing to be time consuming especially in cases where immediate modification and feedback to problems are needed to avoid misunderstandings which could result in serious consequences. SLP participants of FG 1 explained:

**PT 3:** What I would think is that maybe something for voice where you could send a little short thing of point forms but where it's something potentially life threatening like some of the swallowing disorders, I would be very careful about giving that kind of brief information on an SMS (...) I would want to set up something fairly standardised about what sort of information you give and I would still want to follow that up with a phone call.

**PT 2:** Ja, you know what I think the limitation is, is again time consuming where SMS (...) at least on the telephone, if there's a new ... you know; well I put my chin down. No remember I said you mustn't put it down. You know it's an immediate modification of something.

**PT 3:** Yes, there's too much room for a misunderstanding on an SMS with something so important.

**PT 2:** And it's tedious because you're going to have to, you know, they say something, now you, where you could correct immediately or modify or give...

SLP participants of FG 2 further added:

**PT2:** I have two questions; one is, what if you can't spell or you can't type first and second, how do you explain a question over an SMS...

**PT4:** It's very difficult.

**PT2:** So I'd rather sit and wait for them (...) and explain to them and really understand what they are struggling with than me trying to SMS something ...also now you SMS back and front. I need to go and continue with my work...

Sending SMS could result in misunderstandings and would become time consuming. However, large amounts of information would not be necessary post-consultation, if it was ensured that clients understood most of it during consultations. Furthermore, even though reading and compiling SMSs might be difficult for people with low literacy and dexterity, Lurie and Parker (2007) proposed that schools in communities could be enrolled in the quest for improving overall health literacy by not only providing access to literacy classes but also by equipping students to become an "intergenerational" resource for their parents and grandparents. Since more children are enrolled in schools in South Africa than ever before (Children's Institute, 2008), they could be used as facilitators to aid elders with low literacy skills or less experience in SMS technology.

There also seemed to be doubts as to whether clients would initiate contact even when it appeared easier and more affordable for them to get into contact with their SLP. SLPs in FG 2 believed that there are other factors which influence clients' motivation to utilise information technologies for information exchange with health professionals; for example client-specific factors (which have been discussed under section 3.1). While SLP participants on the whole reacted negatively to the suggestion of utilising SMSes, one SLP participant of FG 1 considered:

... I suppose it is something you can think about and try and implement more (...) So we probably could do a bit more in the field of technology with specific clients, definitely [in] the younger generation.

Along the same vein, client participants were generally positive about using SMSes to contact their SLP. They felt it was easier and more cost-effective than having to initiate telephonic contact. Client participants of FG 2 explained:

**PT3 and PT4: (interpreter)** They say however long the question is that they want to send to the therapist, they say it's easy, it's ok they don't have a problem to write SMS, however long the SMS is, they wouldn't mind.

**PT3:** It's a very good idea...Because it's also easier to do it. (...) It's easier than phoning because we need to take a walk...

**PT4:** And sometimes we don't have money to phone.

**PT3 and PT4: (interpreter)** Ja they said sometimes they need to take a walk to the containers there where you use the public phones but sometimes the container is far from their place so if it's free SMS it's much easier for them.

Client participants of both focus groups further agreed that whatever strategy was implemented, it would have to be of low or no cost and easily accessible from home. Considering that personal landlines are scarce and finding a public telephone is not always possible, accessibility and prevalence is less of a concern when it comes to mobile phones.

It has to be noted here that these client participants had not yet tried this avenue of communicating with health professionals and thus might be naïve about the problems that accompany it. However, the fact that it is a cost effective and easily accessible strategy provides reason for trialling the use of mobile phones and their SMS feature for communication efficiency between SLPs and their clients.

### **3.2.2.2. Reminders**

The use of mobile phone reminders to assist clients in recalling important clinical information and recommendations post-consultation was proposed (details in Appendix B). SLP participants explained that the success of this strategy would again depend on clients' literacy skills and their dexterity (e.g. patients who had a stroke might have more difficulties). However, they did not consider that when clients have had CVAs, their caregivers could benefit from reminders of recommendations. Another advantage that was put forward is that - as opposed to written handouts - clients always have their mobile phones with them and thus reminders would be immediate and effective.

Research findings (Kreuter et al., 1999; Osborne, 2008b & 2008c; Santo et al., 2005; Weiss & Coyne, 1997) on how important it is for clients to receive personalised materials with clinical information and recommendations were described to participants and the uses of mobile phone

reminders for this purpose was discussed. However, SLP participants raised various concerns. Firstly, they explained that using this strategy would require additional time from SLPs due to the challenge of compacting long and complex information into text messaging formats which the clients can understand. Furthermore, the researcher realised that SLPs need to get accustomed to each client's mobile phone which (depending on the brand) frequently operate differently to one another. The provision of SMS reminders was only briefly introduced to client participants. These participants yet again welcomed any strategy that would aid them in understanding and remembering clinical information.

### ***3.2.2.3. Audio-recordings (CDs/cassettes/voicemail)***

#### Voicemail

When asked, what they thought about recording consultations as voice-files on mobile phones (details in Appendix B), SLP participants had differing opinions. SLP participants of FG 2 were concerned because one would have to rely on clients to actually listen to the message and at the same time hope that they do not misunderstand it. Messages need to be short in order for them to be effective and understood. SLP participants of FG 2 added:

**PT5:** I wouldn't feel comfortable because I would prefer it to be interactive so I would prefer to phone the person and tell them rather than expect them to listen to my voice message once a week (...)

**PT3:** I think there's no proof that they're doing it right. Like you can have that message. They can hear it 20 times a day, there's still no guarantee that what they're hearing is what they're understanding...

**PT4:** That they interpret it, yes.

These SLPs appear to be more comfortable with being in personal contact with their clients because it allows them to assist their clients' understanding of information and their progress appropriately and on-time. Nevertheless, sending recommendations via voicemails is one way to overcome the issue of low literacy skills and unnecessary expenses. One SLP participant also realised that it is a quick procedure. Rather than having to type important information, one could use the mobile phone like a Dictaphone and quickly record a voice-file for the client to listen to in their own time. This is in accordance with Tattersall et al. (1994), who found that recording consultations has the benefit of only adding minimally to the workload of health professionals.

## CDs/cassettes

One concern of SLP participants about the use of these technologies, was that clients might not have access to the necessary equipment. However, when client participants were asked whether or not they had CD/tape-players and if these were prevalent in their communities, they confirmed that they and most other people in their community do have access to them. It appears that some SLPs may underestimate the prevalence of modern technology in low socioeconomic communities.

Client participants provided positive opinions about this strategy compared to written materials. They explained that an audio-recording is useful for some mothers for example who have their hands full while attending to their child. They could listen to important information about the care of their child rather than having to read written materials which requires undivided attention. Furthermore, client participants of FG 1 realised:

**PT3: (interpreter)** Because a letter, it can be easy to lose it or you can throw water on the letter and you wont get the letter again but the CD, if you throw water on the CD it wont be wet, it will be easy you can just put it in and listen.

**PT3 and PT4: (interpreter)** Yes instead of giving them a letter with point-form it can be easier for them for the therapist to give them CDs. Yes, they said CD is the best because you can hear everything that the therapist said.

A CD or cassette is more durable than written material and significant details which the client views to be important are not overlooked. Tattersal et al. (1994) found that clients reported listening to a voice more reassuring, personal and human than a letter and this was reported by one of the participants here too. One client participant explained:

**PT3:** Yes, as she (PT4) said like maybe she become depressed, maybe the kids are gone, she's at home. If she can put the CD, maybe she going to like, you see, I think it can help.

**R:** Because it is someone's voice that you can hear...

**PT3:** Yes, yes.

Furthermore, when clients do not have enough money to consult the SLP when having forgotten information, they have the audio-recorded information to rely on. Client participants of FG 1 added:

**PT4:** That's a very good idea.

**PT3:** That's also a good idea because some people don't like to read. (...) Yes, because everybody has got a preference, prefer to do this... its all helping to other people or maybe those people who can't read. You get the paper, you just put it there or you ask somebody to read but when you listen, you got your ears you can listen. It's also good.

They thought it was a reasonable strategy for people who do not necessarily like to read or have low level literacy skills as they do not have to rely on others to convey the information to them. Another client participant of FG 1 also emphasised that every person has different preferences when it comes to ways of learning new information, thus SLPs should provide clients with a chance to decide which materials they would like as reminders or materials to review and understand information. She explained:

All of these ideas are good, never the less that we don't have money to come here (not audible), you got something that you can rely on. If you got that CD or you got that SMS or you got that reminder, its also helping as we are different...I like to read, he doesn't like to read. He can better listen or maybe I want to talk to you. I feel better, I'm comfortable. We are all different you see?

This highlights these clients' preferences for personalised information materials and strategies to improve their understanding and recall of clinical information. This also concurs with earlier findings by Hoffman and McKenna (2006) who found that some clients may learn better through visual cues, others through auditory cues, and some through kinaesthetic or tactile cues. People have varying ways of thinking and solving problems which need to be considered.

Reasons for these client participants' largely positive opinions about audio-recordings could be related to the fact that people's interest, exposure, use and positive response to multimedia strategies is continuously increasing (Hui Kyong & Keenan, 2006). SLPs would initially be required to spend extra time on working out a procedure for recording information on different disorders. However, there is no doubt why they should not develop enthusiasm for this particular medium (Doak, Doak & Meade, 1996) after having sorted practicalities behind this strategy.

### **Strategies that were preferred by SLPs overall**

Firstly, when asked to summarise their thoughts and preferences on the most appropriate strategies, SLP participants had difficulties deciding on how to best improve understanding and memory of clinical information in clients who are "high-risk". SLP participants appreciated the idea behind the strategies suggested. However, they were aware of the potential pitfalls and seemed to experience difficulties in weighing up the potential advantages to the potential difficulties. For example, SLP participants of FG 2 felt that they would not typically resort to utilising strategies which involve modern technology. They explained:

**PT1:** I think at the end of the day also, we are speech therapists, we like talking, so technology is fine but I mean if you take a look at the levels of technology around the room...you're probably going to be quite surprised. We're probably not going to use technology as a first line to communicate with patients.

This disinclination towards using strategies that involve modern technology was also expressed by SLP participants of FG 1 who stated:

**PT 2:** Hmm you see technology I again think you're going into the realm of more sort of first world...

**PT 3:** Private things ja, for us...

SLPs (a) assumed that modern technology is not that widespread in poorer communities, and (b) preferred personal contact over any other strategy as it allows them to assist in their clients' recovery appropriately and promptly. It might also be because SLPs are attracted into the profession because they prefer personal, hands-on contact rather than being technologically orientated. At the same time they might not always have enough time and resources to try different avenues of client communication.

Secondly, SLP participants were faced with a difficult task of deciding on strategies to be trialled, although they realised the importance of assuring understanding and recall of clinical information *during* and *after* the session. Still, they continued to focus on the need for additional strategies during consultations. One participant in FG 1 felt that more professional written materials with colour would be necessary and another described the need for anatomical models: They debated:

**PT 2:** I mean the handouts we've got are ones that we've made in our own free time and videos and things I mean a lot of our stuff is ancient and we don't have access to it. You know what I think of almost that the handouts aren't like in advertising they're not you know colourful they're not ...(...) they're not nicely professional, that's the thing. I think if they were more eye catching and in different colours and nice pictures of things I mean we try that but we don't have the time, so maybe a handout that's in, ja like in colour and really exciting sort of pictures, so that might be a good thing...

**PT 3:** I would want one of those big anatomical models where you could take out off the tongue and show them you know cut through the thing.

And at this point one SLP participant of that group realised:

But it's still not take home you see?

Towards the end of discussions, SLP participants resorted to strategies that are already in use (i.e. telephonic contact, bringing another person to the consultation, written handouts, illustrations, repetition, simplicity of language) even though some of their flaws were realised during discussions. Participants ascribed their limited variety of strategies to elements such as lack of resources, budgets

and materials not being professional (i.e. eye-catching, printed in colour). It is interesting that instead of attempting to explore other avenues, these participants preferred finding ways to improve present materials.

All participants were asked to summarise their thoughts on the idea of a possible system that (in addition to all the materials and strategies which are provided in consultations already), would allow clients to review clinical information, ask questions and receive feedback long after they had first consulted their SLP. SLP participants had predominantly positive opinions and they agreed that when more professionals were involved, clients would probably also be more inclined to access certain strategies while another participant speculated that the more ways clients are provided with information, the better. One SLP participant felt that all the while one would have to make sure that information is provided in visual, auditory and tactile form. She explained:

It's almost like you try and give something in each of the senses, in a visual, auditory and tactile, you telling them so you're giving them the auditory input you're giving them something to look at so you're giving them something visual and you also try and give input with the tactile, with actually doing it themselves. So you're trying to do something in each of those three so they've not just heard it they've also got to see it and do it...ahm to try and...

This is in line with the theory by Hoffman and McKenna (2006). Furthermore, these SLPs agreed that their decisions would have to be client-specific (i.e. it would depend on elements like the client's insight and what the client is capable of) and that rather than limiting oneself on one universal strategy, one would have to integrate strategies, as one SLP participant of FG 2 explained:

...I don't know if you will be able to find a universal strategy, you can try, but personally I just find that I'm having to mix and match ...according to the type of person I'm seeing and what I think they are capable of.

## **Conclusion**

When considering all the issues around health literacy and client recall/memory of clinical information as raised in section 3.1. as well as the points raised in discussions above, finding a strategy to address these issues seems like a daunting task. This is probably one of the reasons why SLPs have developed strategies for information processing, recall and exchange with clients during consultations, but they have yet to extend this to clients' everyday environments, the consequences of which have been described. Table 8 in Appendix R provides an overview of all the strategies that were suggested and discussed in focus groups together with their advantages and disadvantages that were identified by the researcher, in the literature review and in focus groups.

### **3.2.3. Strategies to be trialled in phase 2 of this study**

Suggestions and views on health literacy and client recall/memory recorded in the focus groups as well as earlier suggestions by Rao (2007), Kessels (2003), Hugo and Skibbe (1991), Mbananga and Becker (2002) were considered when deciding on strategies to be trialled in phase 2. Furthermore, Andrulis and Brach (2007) warned that developers of information exchange interventions need to be cautious as producers of teaching materials (high tech or low tech) often fail to consider the educational effectiveness and cultural appropriateness of their materials: thus, the adapted Triple Constraints Model was considered in conjunction with proposed strategies.

The following strategies were selected to be trialled in combination: (a) audio-recordings in the form of a CD/cassette, (b) 'please call me' SMS and (c) telephonic follow-up. The reason for this is that an audio-recording of the consultation in the form of a CD/cassette is only efficient in assisting health literacy and recall/memory of clinical information, whereas 'please call me' SMS and telephonic follow-up would only serve to allow for routine reminders, enquiries, discussions and feedback post-consultation. Various advantages of audio-recordings were mentioned in the literature review as well as in discussions by participants. Furthermore, there is a need for research on audio-recordings and other information aids to move into the direction of specifically addressing the needs of "hard-to-reach" clients with low health and general literacy and socioeconomic backgrounds. This medium also accounts for a positive relationship of the adapted triple constraints as it has become more culturally appropriate, it is cost-effective and user-friendly for clients and SLPs.

Not all participants were in favour of SMS as a medium for information exchange and many obstacles were foreseen. However, after carefully thinking this strategy over, the researcher felt that the 'please call me' SMS function provides considerable advantages. A "please call me" SMS is a standard message (no typing required) that can be sent free of charge to another person's mobile phone in order to alert them of this individual's request for telephonic contact. By using the "please call me" function, clients can get into telephonic contact with the SLP at no cost. Even if an individual has low literacy skills, they can send a standard 'please call me' SMS in times of crises or when they have difficulty to recall specific recommendations for example. This feature was viewed to be worth trialling while exploring outcomes for its effectiveness towards reducing the lack of regular contact (post-consultation) between the health professional and clients. This medium also accounts for a positive relationship between the adapted triple constraints as it has become more culturally appropriate, it is cost-effective and user-friendly for clients and SLPs today.

When a 'please call me' SMS has been sent, the SLP could make telephonic contact for follow-up. Post-consultation, telephonic contact has been preferred by many participants as it is an immediate strategy which leaves less room for misunderstandings and it is ideal for crisis management and routine follow-up. Knowing that the only obstacle to using telephone calls extensively is the cost implications, it is hoped nevertheless that when (a) strategies are used to improve health literacy and client recall during consultations, and (b) the audio-recorded information serves its purpose post-consultation, this medium will not have to be utilised as frequently, thus keeping expenditure low. Furthermore, compared to the many additional healthcare costs which would result from clients' non-compliance to treatment regimes, the cost of a phone call to assist in clients' compliance is rather minimal. Telephonic contact has also been praised as a medium for information exchange by Osborne (2008b) who stated that considering the minuscule amount of time that such a phone call costs, health professionals should think of the phone as a time saver and not an interruption or unpleasant duty. This medium of communication also accounts for a positive relationship between the adapted triple constraints as it is culturally appropriate and user-friendly for most clients and SLPs.

## **Conclusion**

There is no one solution to maximising health literacy and client recall and thus it was considered sensible to devise a combination of strategies to assist in (a) maximising health literacy and client recall/memory and (b) assuring an open channel of contact between clients and their SLPs post-consultation. Kagee (2004) also suggested that when wanting to increase the effectiveness of strategies, it would be most sensible to combine them. It was decided not to include low tech strategies as these were already used by the SLPs. However where SLPs provided (low tech) written, illustrative materials, the combination of the proposed (high tech) strategies was *always* added as a further strategy. Even though only the combined (high tech) strategies were focussed on in the study, this mix of low tech and high tech strategies assured the provision of visual, auditory and tactile elements in information exchange during and post consultation.

## **Chapter 4: Results and discussion of Phase Two and Three**

The aim of this section was to evaluate the outcomes of the trialled strategies employed from both the SLP's and client's perspective in four case studies. As this is an exploratory, qualitative study, the case studies were presented and discussed individually and in detail to allow for richness of data (Maxwell & Satake, 2006). Each case study is presented with relevant background and details of the first consultation (details gathered in phase 2) and follow-up appointment. Responses by each SLP and client as well as simple observations by the researcher are discussed collectively under each theme. The researcher's observations were always discussed with the SLP to verify their significance. There may be some repetition across case studies but at the end of this section, the main results of each case study will be compared and discussed. Quotes were only used where strong points had to be substantiated. For complete transcripts of case studies, see Appendices N, O, P and Q.

### **4.1. Case Study One (client with a laryngectomy)**

#### **Background**

This client is a 52 year old Afrikaans speaking lady who stays with her husband on a farm a great distance away from Cape Town. She came to a tertiary hospital in Cape Town six weeks prior to having a total laryngectomy. Due to wound breakdown she had to have a second surgery and spent a longer period of time in the hospital, away from her husband, without any contact with him or other family. During this time she could not speak or communicate in any way other than nodding and gesturing as she had never been schooled and therefore had no literacy skills (she was unable to write her own name). Prior to falling ill she had been working as a domestic worker since she was 14 years old. Her SLP has had 25 years of experience in the field, in public hospitals and with diverse client populations. She is a first language English speaker but has excellent Afrikaans language skills.

#### **First consultation**

The client was emotional at both consultation and follow-up appointments. The SLP counselled the client with regard to voice production, hygiene, anatomy and physiology as well as future needs

(e.g. radiation therapy, speaking valves). She provided illustrated materials clearly showing what was altered and how voice is generated after a laryngectomy, which is customary in initial post-op counselling. As the client did not have access to a tape-recorder, all relevant information was recorded onto a dictaphone during the session. In addition to pictographic illustrations to take home, arrangements were made to use the house sitter's mobile phone (with permission) to send "please call me" SMSes and receive subsequent telephonic follow-up. The procedures of how to use the strategies were explained once more before the client left the consultation. There was a period of three weeks between the first consultation and the client's next follow-up appointment.

### **Follow-up appointment**

The client presented with various concerns at her follow-up appointment. The entire pre- and post-operative experience had been emotional and traumatic for her. The client had not been practicing speech very much after her operation because the client spent most of her time alone at home. Furthermore, lack of support from her husband appeared to have an additional negative effect on her emotional well-being. The couple experienced serious financial difficulties, as a result of the client's inability to work immediately after her operation and her husband's ill health. In addition, the client's employer had concerns about whether or not to employ her again. The client's lack of communication practice negatively affected the flow of discussion during the interview.

### **Evaluation and discussion of data gathered in phase three for case study one**

#### ***Improvement of health literacy and recall of clinical information (long- and short-term)***

The combined strategies did aid this client in reminding her about the stoma and problem-solving for her difficulties with voice production. However, there were various factors which had an impact on her ability to effectively use the strategies for recall and understanding of clinical information as well as problem solving. When she had first left the consultation, she had no problems with immediate recall of the most important information and her understanding was confirmed at the end of the consultation when the SLP questioned her on what had been explained. However, she reported that she forgot some details when she eventually arrived at home which is when she used the audio-recording to refresh the information in her mind, thus indicating her need for a strategy to review information once she was at home. She also found it helpful to listen to a voice during the day when she was alone at home, to review information and for reassurance. She explained:

**P1:** Deur die week as ek so alleenig is, dan sit so, dan sit ek hom aan.

**R:** So was dit ook net om vir mevrou, dat mevrou (the speech therapist) se stem gehoor het en...

**P1:** Ja...<sup>6</sup>

This concurs with findings by Tattersal et al. (1994) who found that clients frequently found listening to a voice (audio-recording) reassuring, personal and human.

As the client did not have exclusive access to a mobile phone, she did not have a chance to get into contact with the SLP any time she needed to. Even when the SLP contacted her employer to ask if they could speak to this client and ask if she was coping, the employer responded that they received a message from the client to say that it was going well with her. Meanwhile the client was in pain whenever she had to put a tracheostomy tube in at night, which led her to leave it out completely and as a result her stoma closed to the point of near suffocation. There may have been two reasons for the client not taking the opportunity to explain and discuss her problems with the SLP. She may not have had the necessary privacy or she may have felt uncomfortable having to use this person's private mobile phone. Whether or not she would have gotten into contact for immediate problem-solving more readily if she had had her own mobile phone remains unknown. Osborne (2008b) found that clients and their families seldom take advantage of telephonic contact but she suggested that even though it might take a while for clients to realise their responsibility in making contact with their SLP, clients do become more self-efficient after a few "practice-sessions" with the help of their health professional (Osborne, 2008d).

In the questionnaire, the SLP agreed that when the client had left the consultation, the information that she was taking with her was clear, accurate and complete and ready for review to improve understanding and recall of clinical information at any stage post-consultation. However, it appeared that anxiety and trauma had a considerable impact on this client's ability to problem-solve and effectively manage her own health. The SLP explained:

Hm, because of her trauma and her situation just precluded her benefiting from it. (...) Anxiety, trauma, adjusting to life outside of the hospital...all those psychosocial issues come into play...

This concurs with the literature on factors that impact adherence to clinical recommendations (Fitzner & Fielding, 1994; Flocke & Stange, 2004; Ley, 1979; North et al., 1992; Stone, 1979). The effects of anxiety and trauma have also been identified as variables to compliance in phase 1 of this study. Having to adjust to life outside the hospital is an additional variable that clients who have had laryngectomies have to deal with and because this client was not supported by people in her

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<sup>6</sup> **Translation:** P1: During the weeks when I was so alone, I would sit and I put the tape on and just listen. R: So was it also just that you could listen to the speech therapist's voice? P1: Yes.

immediate environment and through strategies, she may have had more difficulty in doing so (Engelbrecht et al., 2006; Deverell et al., 2004).

When discussing whether or not the SLP felt that there was an improvement of health literacy and recall of clinical information in the client, both the SLP and the researcher realised that even though the client reported that she found the audio-recorded information helpful for review and recall, rather than helping her to adhere to recommendations, it aided her in a more supportive fashion; to feel comfort and come to terms with her situation. The SLP and the researcher further recognised that at that stage of the clients' recovery, the strategies did not serve the purpose of aiding her in managing her own health and knowing when to seek help. Possible reasons for this were discussed. The SLP realised:

Hm, it's just too much at that new point in time, that acute stage.

According to the SLP, it is difficult and takes time for these particular clients to come to terms with their circumstance even when they are insightful. During discussions, the SLP and the researcher further realised that whether or not clients cope well is not only an indication of whether or not they have understood and remembered important clinical information but also whether or not they are burdened by emotional variables (Fitzgerald Miller, 1992). The known psycho-social trauma of laryngectomy will have played a role here (Deverell et al., 2004). Again, the SLP stated that it is very unpredictable. She explained:

It takes time...even with the insightful clients (...) I have had illiterate shack dwellers do exceptionally well and I've had high intelligent (...) businessmen not do well because they're just depressed (...), so it's unpredictable...

When the degree of these emotions is high, an individual could become incapable of thinking objectively and making sensible decisions about a health problem (Rosenstock, 2005). Even when a client is offered a more effectual strategy for handling their situation, they may not accept it purely because they experience difficulties in thinking constructively about the health problems at hand (Rosenstock, 2005). This client's difficulties with self-care and compliance may have been as a result of her lack of problem-solving skills, experience, or confidence at the time which she needed to think of herself as being capable of managing her own health (Osborne, 2008d). Another factor was that this client was left alone with no one to speak to or assist and support her most of the time. She only had her husband to turn to. However, when she tried to explain her situation to him she found that:

Hy was baie ongeduldig... (...) Hy het altyd net geluister maar hy wou nie eintlik met my praat baie met my nie. Al wat hy sê is hy kan dit nie verstaan nie, hy kan dit nie glo nie...dat ek so lyk. (...) Sy antwoord is net hy kan dit nie verstaan nie...hy kan dit nie glo nie, hy kan nie vergeet nie.<sup>7</sup>

It appeared that he was in denial and at times somewhat intolerant towards her. In addition she had to deal with the stress of their financial situation, all variables which impacted her ability to comply with her treatment regimen and manage her own health. These factors and demands of daily living may have been catalysts for her feelings of hopelessness and confusion, which may have further clouded her judgement and prevented her from effectively managing her own health (Ciechanowski et al., 2001; Fitzner & Fielding, 1994; Flocke & Stange, 2004; Kagee, 2004; Ley, 1979; North et al., 1992; Stone, 1979). The client explained:

Ek het gewerk, ek was gesond...ek was altyd gelukkig. (...) Maar nou...<sup>8</sup>

It appeared to be difficult for her to get used to her current situation in the presence of knowing that she had previously been healthy, happy and working. At this initial stage of recovery, much of her energy was spent on yearning for her previous life and coming to terms with her present situation, rather than problem-solving and managing her own health and future (Blood, Luther & Stemple, 1992; Feifel, Strack & Nagy, 1987). All of the above demonstrates that a great deal of social support was needed here in order for the client to regain quality of life. This could only have been provided through involving the family and her employers. In addition, contact (through SMS and telephone) with the SLP as well appropriate referrals where needed. Even though the SLP had done everything in her power to assist this client post-consultation, there appeared to have been a shortage in the provision of support and intervention by all parties that came into contact with this client.

***Satisfaction related to the value that is placed on the strategies or the extent to which the participants found them to be helpful***

The client participant felt that an audio-recording of the most important points discussed in a session was a “wonderful” idea and should be given to every client. Even though these strategies were not effective in managing her own health or inform her husband, she found that there were times when she had forgotten some details about her treatment and by having an audio-recording to refer to for review of this information, she was able to remember and understand it. This concurs with findings

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<sup>7</sup> **Translation:** He was very impatient. He listened to me and to the tape but he did not really want to talk to me. All he says is that he cannot understand or believe that I look like this. His answer is always that he cannot understand, he cannot believe and he cannot forget what happened.

<sup>8</sup> **Translation:** I worked, I was healthy, I was always happy. But now...

by Tattersal et al. (1994), who found that clients particularly preferred an audiotape with information provided during consultations because it contains details of information and reassurance which further assist in compliance.

During the discussion, the researcher and SLP both realised that even when one develops and provides various supportive strategies to assist the client managing their own health, it ultimately still depends on the client themselves and aspects like motivation, insight and problem solving skills whether or not they will be able to successfully comply with treatment. This was also mentioned by SLP focus groups in results of phase 1 (section 3.1.). However, both the researcher and the SLP wondered whether or not the effectiveness of the combined strategies and the client's ability to focus and successfully manage her own health might come at a later stage. The SLP emphasised:

Yes, so again you know it can be... it might not work, so these strategies might not work in the first instance but also repetitively on an ongoing...

The strategies may work at a later stage, when utilised in a repetitive and ongoing fashion throughout treatment. As the client's coping improves with time (Blood et al., 1992; Feifel et al., 1987), their ability to readily focus on utilising strategies to manage their own health may improve (Blood et al., 1992; Fitzgerald Miller, 1992). Whether or not there are different outcomes of the combined strategies at different stages of a client's road to recovery could be an interesting topic to investigate in future research.

After the main part of discussions, the SLP showed that she generally did have a positive attitude towards the combined strategies when she stated:

... Well I think positive in that we have to see what we can do to help illiterate people and to get the message across...so I think don't discount it.

However, she did experience some frustrations, which led her to think that the combined strategies were not indicated for every individual. This is further discussed in the next section.

***Is the combination of the strategies usable in the intended environment and for the intended purpose? (SLPs' and clients' attitudes towards using the strategies in future)***

In the questionnaire, the SLP revealed that the combination of the strategies were an added burden as this client had no experience with audio-recorders or mobile phones. She explained that they were impractical because she had to educate around the strategies in addition to giving the client a lot of information. The SLP further doubted whether she would use these combined strategies with a

similar client in future because they did not assure regular contact and they were unnecessary and inappropriate. The SLP stated:

I kind of got to know her and her lack of experience in these. I also know that she was mostly alone at home and she just had a husband who didn't really appear very supportive and she wouldn't be the one that would go to the white lady, you know that's not always around (to ask for her mobile phone) so she was fairly isolated so in her case probably... not that indicated.

Although this client did not benefit from the combined strategies, the SLP did feel that initially it was time well spent with a client who was illiterate. She explained:

... it's worth trying I think in people who are illiterate you want to try as many avenues if you can...

The SLP continued that the combined strategies should be an added way to facilitate understanding and recall in clients. In laryngectomy cases, she preferred telephonic contact and "please call me" SMS because verbal reinforcements and clarifications can be provided immediately when needed and clients are ultimately made responsible for themselves (i.e. they need to decide when to initiate contact). This is particularly important when managing laryngectomies where clients have different needs which have to be addressed by a whole team of specialists (Engelbrecht et al., 2006; Deverell, et al., 2004). It is a life-long attachment to a hospital and a therapist and they have to attend frequent appointments (Engelbrecht et al., 2006). Audio-recorded information might be more effectual in cases where management is more clear-cut, straight forward and not critical (as in voice disorders or stuttering therapy). Differences in disorders and resultant needs for strategies were also revealed in section 3.1.

Discussions continued to investigate what could be done differently for clients (with laryngectomies) who are illiterate, come from rural areas and have a poor socioeconomic background. The SLP explained:

With laryngectomies I don't really know. I think if they don't have easy access because they often need medical attention... You know none of the strategies might be superb... because it's not just depending on them. It's not like a dysphagia where you say; remember to put your head down when you swallow! Ahm... there can be infections, there can be small stomas, there can be... prostheses fall out and then what you've taught them is just for if everything is fine. If everything isn't fine they need medical attention so...

No single strategy might be outstanding because there will always be unforeseen problems that need immediate attention from various professionals which also highlights the need for regular contact (through SMS or telephone). The SLP also explained that while the combined strategies are a "good idea", it cannot be a blanket technique for all illiterate clients with poor socioeconomic status or who

cannot frequently attend therapy. SLPs would have to be selective when deciding to use the combined strategies or just parts of them to assist the client in complying with treatment.

The SLP continued by addressing some issues that need to be dealt with in cases where it is decided to provide audio-recording information to these clients. Firstly, one would need to be much more selective of what is recorded rather than recording lengthy detailed discussions and explanations. Secondly, the recording should be conducted right at the end of consultations and information should be presented in point-form including relevant information for the family (or in this case the client's partner) which could facilitate their acceptance, understanding and support. A similar suggestion was made by the client who proposed that a letter be provided specifically to significant others for frequent review and reference to the client's treatment. This is a reasonable suggestion when the other person can read. Alternatively, if they cannot, the same information can be recorded for significant others to listen to and review when needed.

***Do users need more training and guidance in order to use the strategies appropriately?***

It would inevitably take some time for (a) the client to be using the strategies appropriately and more readily and (b) the SLP to work out the best procedure and protocol for when to implement these strategies. With practice, it should be easier for clients and SLPs to use the combined strategies for their benefit (Doak, Doak & Meade, 1996).

***Effects that the combined strategies have on structural or process quality (e.g. time saving, clinical workflow)***

When discussing the value of the combined strategies to other health professionals, the SLP realised that they may in fact be unfamiliar with these strategies and it may be easier for them to read clinical notes or get into telephonic contact with the SLP when wanting to manage this client. However, even though the audio-recording may not be of any benefit to other health professionals who come into contact with the client, the client could effectively explain their situation and previous recommendations as they have had repeated opportunities to review the information. As a result, less time may be needed for other health professionals to get to know the client's presenting issues.

Another factor that was also raised was the issue of interpreters, whose services are needed when recording information and during telephonic follow-ups. Unfortunately, trained interpreters are still scarce (Penn, 2007; Roberts, 1997) but where they are available, it should be of high priority that their services are used during consultations and when utilising the combined strategies.

## **Conclusion**

In this case study, strategies that were used included counselling, illustrations, audio-recording, the option of a “please call me” SMS and telephonic follow-up. This particular client had poor recall and health literacy skills possibly related to poor insight, motivation and additional stressors and variables. She spent much of her energy on longing for her previous life and coming to terms with her present situation, rather than performing self-care and managing her own health and future through the use of strategies (Fitzgerald Miller, 1992). The question is whether or not the client would be better equipped to manage her own health after she had time to deal with her situation, regain confidence and practice using the combined strategies to her advantage.

Furthermore, the impact that dynamics in client-provider relationships have on the success of client outcomes have frequently been cited in this study. In this case it was observed that the SLP was caring and she spoke to the client in a manner which was clear and in accordance with the client’s level of language and insight. This is why the SLP’s accommodating and considerate manner in which she managed the client in this case is so important (Ciechanowski et al., 2001; Kagee, 2004; Roberts 2002). The SLP saw the value of the combined strategies but she was aware that they might not be a single universal technique to use with any client.

## **4.2. Case Study Two (caregivers of a child with cleft palate)**

### **Background**

Two caregivers came to a tertiary hospital where their baby boy was born seven weeks prematurely. He was born with a cleft of the hard and soft palate and thus required management by a feeding specialist - a SLP. Both parents were from Somalia. At the time of the study, they were unemployed and they did not have sufficient English literacy skills. Their English language skills were however adequate enough to understand clinical information and ask important questions during consultations. The caregivers were kind and caring and they were always enthusiastic about how they could assist in their baby’s health management. Their SLP has had 16 years of experience in the field and in working in public hospitals with this client population. She is a first language English speaker.

## **First consultation**

The child was referred to the SLP for a swallowing and feeding assessment. The therapist started with oral stimulation techniques. These techniques were explained in addition to details about the aetiology and location of the cleft palate. Associated problems and future expectations were added. Unfortunately the SLP did not have any illustrations at the time to show pre- and post-operative cleft palates and no pamphlet or any other information brochure was provided. All important information and answers to some of the caregivers' questions were recorded on a CD for them to take home. They were also provided with the SLP's mobile phone number and a respective "please call me" code. Even though they knew what the "please call me" SMS was for, the procedure and when to use it was nonetheless explained. Both caregivers had mobile phones but admitted that they infrequently had airtime. The child stayed at the hospital for a week before he was transferred to another tertiary hospital where he stayed for a further 3 weeks. There was a period of four weeks between the first consultation and the client's next follow-up appointment. During this time, the caregivers only sent one "please call me" SMS one evening because they were both in distress and they felt that SLP could assist. Their concern was however a medical problem

## **Follow-up appointment**

At the follow-up appointment, only the mother was present. The baby had gained weight and she was pleased. It was revealed that she was following the recommendations appropriately and she knew what the rationales were. This time the child was seen by both the SLP and the plastic surgeon. The SLP explained that the client would only have to come again after nine months when the child would engage in speech development. Further information was provided about the importance of speech development and stimulation as well as proceedings in feeding. Once more, no illustrations were provided but from the questions that the mother asked, she appeared to have gained adequate insight into her child's future health management.

## **Evaluation and discussion of data gathered in phase three for case study two**

### ***Improvement of health literacy and recall of clinical information (long- and short-term)***

During the discussion, the SLP and the researcher both realised that it was difficult to determine whether or not the audio-recorded information made a difference in the improvement of knowledge and recall of information in this case. The caregiver reported that they understood everything from

the beginning and the SLP and researcher also agreed that they appeared reasonably insightful. This is also why the SLP was undecided about whether or not the combined strategies were a waste of time or time well spent in this particular case. It was debated:

**R:** (...) I couldn't really say, you know did the CD now really make a difference because they were fine...it could have been that it was because they were able to listen to the CD...

**T2:** Hm.

**R:** ...or it could have been that they just understood from the beginning...

**T2:** Ja so it's difficult to measure that outcome...

The caregiver explained that even though they had initially understood and could remember everything when they left the first consultation, they listened to the audio-recording frequently to be reminded of how to manage the child's health. She found that they were provided with much information and without the CD for review, she would have forgotten most of it. Yet again, this concurs with findings by Tattersal et al. (1994), who found that a reason why clients particularly prefer an audiotape with information provided during consultations is because it contains details of information and reassurance which further assist in compliance.

***Satisfaction related to the value that is placed on the strategies or the extent to which the participants found them to be helpful***

During discussions with this caregiver, various reasons for their enthusiasm for a CD could be identified and these had little to do with the improvement of recall and knowledge. In addition to her being able to review information, the caregiver felt it was also beneficial to share information with others. It was apparent that the neighbour said:

She say it's nice, doctor give to you the CD, reminding you every time your baby...they say yes it's nice talk (not audible).

The SLP and the researcher further debated:

**R:** Do you not maybe think that having a CD, which is such a modern thing...maybe that it will actually increase them wanting to comply...?

**T2:** It might...

In addition to the CD being a valuable and new way for sharing information, it was interesting for her husband to hear himself and the conversations they had with the SLP, which shows that the ability to share information with family and friends and the inclusion of "both parties" as participants in the consultation is valued highly by some clients (Stockler et al., 1993).

Overall, the caregiver agreed that she had a positive experience of the Speech-Language Pathology treatment and management of her child's problem. This was revealed during the following discussion:

**R:** ...what is your overall feeling with this whole...

**P2:** Hospital?

**R:** ...just say like with the Speech Therapist...

**P2:** No, really nice...

**R:** Are you happy? Ok. And why do you say so? What are the reasons?

**P2:** Because you help me for my baby you see. Me I don't know if he got [not audible]. But doctor tell me and she show me, she open his mouth and say you must look there...you understand? So that's why I'm happy.

The SLP took time to explain the situation to them and made sure that they understood and remembered the most important clinical information. It also seems like the SLP's manner in which she treated the clients was important for them to be able to feel comfortable and equipped in managing their child's health (Ciechanowski et al., 2001; Kagee, 2004; Roberts 2002). The caregiver recommended the provision of the combined strategies to other clients. Even though they sent the "please call me" SMS during a time of desperation and with a problem that was not related to Speech-Language Pathology management, she thought it was beneficial that they were able to have this strategy at their disposal. This shows that, though not used as initially expected, "please call me" SMS and telephonic follow-up are strategies that can accomplish the purpose of allowing clients to get into contact with a health professional when in need and at no cost.

In the questionnaire, the SLP felt that the combined strategies were appropriate and user-friendly. She explained that the caregivers had exclusive access to mobile phones and a CD-player and even though their English language skills were not high level, they were able to understand and speak it sufficiently. In the questionnaire, she also agreed that when clients left the consultation, information that they were taking with them was clear, accurate and complete and ready for review at any stage post-consultation which was viewed to be important for assuring clients' compliance to treatment by Kessels (2003) as well as Flocke and Stange (2004). Furthermore, the SLP also agreed that the combined strategies were (a) effective in assuring continued contact and service-delivery post-consultation, (b) suitable for information review by other family members, and (c) generally effective in improving health literacy and recall of clinical information, thus increasing the efficacy of treatment that she provided.

***Is the combination of the strategies usable in the intended environment and for the intended purpose? (SLPs' and clients' attitudes towards using the strategies in future)***

Even though the SLP found the combined strategies to be of assistance as described above, she did feel that they were not practical for her because they would take time and she would have to invest in a system that would record and burn CDs or tapes. She would also always have to find a quiet room which is not easy in a hospital and it would require a lot of additional planning which would be more of a burden than of assistance. She further explained that these particular clients might also struggle with making sense of the information later, when it is out of context (at home). This concurs with findings by Ley (1979), who explained that (in addition to time delays) a mismatch between the clinical contexts and home environment might hamper memory retrieval and understanding of information. Alternatively, the SLP suggested that only a mobile phone number instead of a CD were provided as it was quicker and easier, there was less room for misunderstandings and no need for additional expensive equipment to be bought. However, if clients do not get into contact with the SLP and ask for clarifications, they might misunderstand or not remember information and implement the wrong feeding technique.

In the questionnaire, this SLP indicated that there is a difference between disorders and the need for (or possible effectiveness of) the combined strategies, which is similar to what the SLP in case study one suggested. This SLP explained that in cases of voice clients for example CDs with clinical information would be more practical where principles of therapy are more generic and you can easily record and make sense of them. Another example that she provided was that of articulation therapy for children, where she could record a session and the caregiver could follow the whole program at home. In cases of clients with dysphagia or laryngectomies, this is more difficult as disorders are more acute or critical and hands-on guidance as well as practical demonstrations are needed (Low et al., 2001; Sataloff, 2006). In these cases, visual tools like a video-recording would probably be more appropriate because information is presented visually and in context whereas if it was presented only auditorily and out of context, information might be less clear. However, she explained that having to create video-recordings might be just as impractical as audio-recordings. It would initially take additional consultation time and she would have to invest in a system that would record videos or DVDs.

Even though the SLP suggested the primary use of “please call me” SMS and telephonic follow-up, it does raise the likelihood of the SLP being consulted on issues outside of her scope of practice. According to this SLP, clients tend to generalise any aspect of their care to the responsibility of one

health professional and this puts unwarranted pressure onto that health professional. The question is whether clients do this generally or out of desperation which would indicate their need for a strategy that would assist in managing their (or their child's) disorder when there is a crisis.

No matter what strategy one decides on, there will always be some risk or trial and error period (Doak, Doak & Meade, 1996). The combined strategies might not be a universal tool and it depends on each client and their respective SLP, which aspect of the combined strategies they see fit to use. However, should one completely discard audio-recorded clinical information for clients, the issue of how to aid clients who have no or low level literacy skills in their review and processing of vast amounts of complex information will still remain.

***Do users need more training and guidance in order to use the strategies appropriately?***

It would inevitably take some time for the SLP to work out the most suitable equipment, best procedure and protocol for the implementation of these strategies (Doak, Doak & Meade, 1996). Clients who are used to accessing the media that make up the combined strategies, would need less assistance in *using* them per se but rather in effectively and appropriately utilising them to manage their child's (or their own) health.

***Effects that the combination of these strategies have on structural or process quality (e.g. time saving, clinical workflow)***

The SLP felt that the combined strategies were unsuitable for information review by other professionals mainly because they will not have the time or access to the facilities that are needed to listen to an audio-recording. She emphasised that it would remain easier for other health professionals to read through clinical notes or follow-up with the respective SLP telephonically. The caregiver might be able to effectively explain their situation and previous recommendations as they have had repeated opportunities to review the information which may save other health professionals time when having to investigate the client's past treatments through records or telephonic follow-up.

This SLP also highlighted an issue that was discussed in case study one, namely that of interpreters. She explained:

...it was fine with them, but if you have someone with a lower level of English it is going to be...you definitely need someone to interpret because otherwise it is going to be a waste of time.

She felt that the combined strategies were not useful for people who did not have sufficient English language skills as you needed an interpreter there during recordings as well as when returning phone calls. As was mentioned in case study one, the reality is that these agents are not always readily available (Penn, 2007; Roberts, 1997) but efforts should be made to include them in management of clients with insufficient English language skills at all times.

Another concern was that the child was not immediately released to go home but referred to another healthcare facility where he remained for a couple of weeks. Even though the mother would feed her child during that time, the hospital staff was ultimately in charge of the child's health management and these professionals did not have access to the combined strategies. The SLP explained that the nurses need to be equipped (either through general informative videos or audio-CDs) so that they were able to manage a child with cleft palate. This raises the issue of information exchange between health professionals (McWhinney, 1997; Wood, 1993), which is beyond the scope of this discussion. On the other hand, the above also indicates responsibility of the caregivers, if they do not inform other health professionals or provide them with the strategies that were provided to them in the first instance.

As described in the literature review, differences in culture have been found to impact on compliance (Bunning, 2004; Zhang & Bennet, 2001), but in this case, it did not seem to have interfered. One could have thought that being from another country and another culture would make these caregivers more wary of the local health professionals, but this was not the case. The caregivers were motivated to work as a team with the health professionals to effectively manage their child's health.

## **Conclusion**

In this case study, strategies that were used were counselling, an audio-recording and the option of a "please call me" SMS and telephonic follow-up. Management in this case was effective and the SLP had a positive experience when using the combined strategies for improving health literacy and recall of clinical information. It was not clear whether the success was due to (a) the combined strategies being of real assistance or (b) the caregivers being insightful and motivated from the beginning or (c) a combination of both the combined strategies and the caregivers' insight and motivation that contributed to this case being managed without any significant problems. Nevertheless, the clients did not have any written information to refer to which suggests that the

combined strategies were important when clients wanted to review information. This provides a contrast to case study one, where there was a lack of insight and motivation which impacted that client's compliance. The SLP saw the value of the combined strategies but had concerns for their future use.

The question that stands out after having analysed these two case studies is whether or not this specific combination of strategies would perhaps be more effective with disorders that are less severe, complex and acute.

### **4.3. Case Study Three (adult client with dysphagia)**

#### **Background**

This client was a 41-year old man, who had been referred to the SLP at a rehabilitation clinic, after discharge from hospital. He had suffered a traumatic brain injury a few weeks before, and now suffered from moderate dysarthria and experienced eating and swallowing difficulties. He was using a wheelchair and his wife was now the sole provider of the family with two children. She was employed as a domestic worker. They were living in informal housing with no running water or electricity. During the day, the client's sister took care of him. She lived in a house a few meters away. This couple did not have a car. His wife sometimes pushed the client in his wheelchair more than 5 kilometres to the clinic, and when they had enough money, they would hire a taxi. The only mobile phone which they owned had been lost recently. Thus, the sister's mobile phone was used in cases of emergency. Both the client and his wife's literacy skills were reported to be functional even though they both only completed grade four and they admitted to having difficulties with reading complex text. The client's SLP has had 2 years of experience in the field and in working in public hospitals and clinics with respective client populations. She is a first language English and Afrikaans speaker.

#### **First consultation**

A document with clear advice and illustrations of exercises (including the number of times that they had to be performed) was provided. As a result of the client's lack of electricity, a dictaphone with recorded information was provided. On it were reasons for difficulties with speech, eating and swallowing, details about the procedures for performing the exercises and alterations of feeding

techniques and food consistencies. In addition to the audio-recording and illustrations, clients were provided with the SLP's mobile phone number and a "please call me" code. The procedures for the strategies were explained once more before they left the consultation. There was a period of two weeks between the first consultation and the client's next follow-up appointment. No "please call me" SMS was sent during the time between the first consultation and follow-up appointment.

### **Follow-up appointment**

The SLP asked what exercises the client had been practicing and whether there had been an improvement in his swallowing and eating difficulties. He was easily able to name and demonstrate the exercises and he reported great improvements in his consumption of certain foods and liquid. Spontaneous recovery (Nevada Care Connection, 2009) had occurred and the SLP explained that the client needed to continue with the previous exercises. She added one new exercise and recommended that he continue with the modifications to everyday food consistencies and his eating practices.

### **Evaluation and discussion of data gathered in phase three for case study three**

#### ***Improvement of health literacy and recall of clinical information (long- and short-term)***

The couple did not contact the SLP because, they felt that everything went smoothly. Both the client and his wife reported that even though they did not have any difficulties remembering and understanding the information provided to them when they had initially left the consultation, the audio-recording was of most assistance post-consultation, when they felt the need to review the information. They agreed that in addition to the illustrations and the written information in point-form, the audio-recorded information assisted when wanting to review details of the exercises etc., which they would have forgotten otherwise. Santo et al. (2005) also named these as advantages of audio-recorded information.

In the questionnaire, the SLP agreed that the strategies were generally effective in improving health literacy and recall of information in this couple. Furthermore, she felt that the strategies were effective in promoting compliance or behavioural change and she thought that they made a difference in the success of the client's treatment. She explained that:

... the client seemed like he had more resources to work with, he was more motivated to do his task... he was more motivated because he could take ownership and responsibility for his therapy because he had something in

his hand you know to look back at and to refer back to all the time. So for me I feel that now, where you actually give the client a tape or you give the client the page, then it's them taking the responsibility and saying; ok I need to work on my thing now. So I think it's quite beneficial because if the clients leave without something, then I often find that they forget everything and they don't take that responsibility.

The SLP felt that the couple appeared confident in managing the health of this client and they were interacting with the information better than other clients that were less equipped would have. As an example she mentioned the fact that generally clients are not able to easily recall much of the initially provided information. This client however, did well when asked to describe the advice and recommendations given to him at his first appointment. The above concurs with findings by Kubeck (2002) and Rosenstock (2005) who emphasised that clients' confidence in their own abilities and self-efficacy needs to be upheld, and they need to fully comprehend what is being discussed during consultations in order for them to stay motivated.

The SLP continued to explain that equipping clients with strategies to improve health literacy and recall was also beneficial to the therapist as an assurance that everything possible was done for the client to understand and remember what was discussed during consultations. She added that as a result, continued service delivery is assured and simultaneously, it puts some responsibility into the clients' hands.

***Satisfaction related to the value that is placed on the strategies or the extent to which the participants found them to be helpful***

Overall, the couple appeared to be pleased with the progress that had been made and they did not have any major concerns. They explained:

**P3:** Alles het goed verloop. (...) Die kos en die water...dit het goed gegaan...soos sy (his wife) verduidelik het.

**C3:** Ek is maar net bly vir die hulp wat ek ontvang en as dit vir hom kan beter maak dan is ek bly daarvoor.

**P3:** Dit is eers goed wat julle doen. (...) Ek sê 'baie dankie' wat julle vir my gegee het en wat julle gedoen het.<sup>9</sup>

Furthermore, the audio-recorded information was beneficial when clients wanted to inform family members and significant others about this client's Speech-Language Pathology treatment. When she spoke about her family and the relevance of the strategies at this point, she explained:

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<sup>9</sup> **Translation:** Everything went well.(...) The food and water...it went well...as she (his wife) has explained. C3: I am just grateful for your assistance. If it can make him better...then I am grateful for that. P3: It is good what you do (...) I say 'thank you' for what you have provided to us and what you did for us.

(...)... hy (her son) het geluister...soos ek nou kan sien is hulle maar net bewus wat aangaan... (...) Sy (the sister-in-law) het gevra; wat is dit? Toe sê ek dit is die oefeninge wat hy elke slag kry vir sy mond om sy spraak te laat bykom, tongoefeninge en alles. Nee sy het nou gesê dit is iets goed, vir die vergeetslag.<sup>10</sup>

Santo et al. (2005) also emphasised that being able to review details of treatment through audio-recorded information is especially important when two or more individuals share caregiving of a client, as in this case study. The wife was able to give detailed explanations about her husband's treatment to the client's sister and at the same time, the sister was equipped to get into contact with the SLP when in need and at no cost. The audio-recorded information was probably of most assistance to family members and people in their immediate environment as the illustrations and the information in point-form would not have made much sense to them without detailed explanations (Stockler et al., 1993).

When asked whether they would have still forgotten even in the presence of the illustrations and the recommendations in point-form, they explained:

**P3:** Ja.

**C3:** (...) Die tape gee meer duidelikheid. (...) Kyk ons kry mos nou die oefeninge, maar die is mos nou n prentjie wat hier op is, die prentjie kan mos nie praat nie, maar as dit soo...die pasiënt en die spraakterapeut praat met mekaar. Sy verduidelik vir hom wat aangaan en nou doen hy dit. (...) Daar is meer n verstandhouding tussen die twee, want dit word gedoen en dan word hy mos nou hierop gespeel. (...) ...dit is mos nou iets werklikheid wat mos nou plaasvind.<sup>11</sup>

Furthermore, the couple felt that access to "please call me" SMS and regular telephonic contact would have been most beneficial initially when the client had first come out of the hospital. He had experienced various difficulties with his speech in addition to frequent aspiration and it would have made them feel safer knowing that they could receive immediate support when needed. Thus, it is indicated that at the initial stages of treatment, the need for professional support and empowering strategies to manage their health, is vital (Blood et al., 1992).

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<sup>10</sup> **Translation:** He had listened and as I have seen, it just made him more aware...She had asked; what is this? And I explained to her that these are the exercises that will improve his speech. She said that it is something valuable to help with remembering it all.

<sup>11</sup> **Translation:** C3: The tape provides more clarity. Look we got the exercises but this is just a picture and the picture cannot speak...but the patient and the speech therapist speak with each other. She explains what is going on and he follows her advice. There is an understanding between the two because what is discussed in the session is recorded on here. It is something that happens in real-time.

The SLP further recognised the benefits of the combined strategies, especially post-diagnosis, when clients are most worried and distressed. She reported that she frequently experienced that when clients have arrived at her clinic for an appointment, they were uncertain about what their diagnosis was and what their treatments were. They had traumatic experiences and were faced with major psychological and social problems since the onset of their condition/disorder. In cases like these she has to first take the time and inform clients about their (or their child's) situation and make appropriate referrals. She emphasised that during this time it is most important that the SLP is available to clients at any stage post-consultation. Here, the "please call me" SMS and subsequent telephonic follow-up would become a salient strategy together with audio-recorded information for the review of information once the client has had the chance to gather themselves at home. Yet again, it is demonstrated that the combined strategies might have different functions and possible outcomes at different stages of recovery.

In the questionnaire, the SLP agreed that the combined strategies were necessary, user-friendly, culturally appropriate and practical. She explained that the clients had access to a family member's mobile phone and even though they did not have electricity, they could review detailed information by using a dictaphone. The SLP also found that the combined strategies were useful for these clients who live in an impoverished area and could not easily come for appointments. She felt that providing the combined strategies to this couple was time well spent and did not require any extra therapy time. When clients had left the consultation, the information that they were taking with them was clear, accurate and complete and ready for review, to improve understanding and recall at any stage post-consultation which was also viewed to be important for assuring clients' compliance to treatment by Kessels (2003) as well as Flocke and Stange (2004).

Later, the SLP explained that she thought the combined strategies were appropriate for all disorders listed; namely dysphagia, voice disorders, laryngectomy and cleft lip and/or palate management. All these disorders require the therapist to obtain regular feedback from clients because the status of these disorders frequently change and new problems occur. For example, there might have been spontaneous recovery (Nevada Care Connection, 2009) or regression in the client's therapeutic process. She explained:

Especially with the dysphagia clients, I noticed that they often recover quickly or they have different problems. (...) so I feel they need to be monitored closely because maybe on the first day you see that your aims are specific and then the next time that you see them the aims are different because (...) there has been spontaneous recovery,

there has been some regression. So, in order for my therapy process to be guided, I need to get that constant feedback from the client all the time.

She agreed that this is also where “please call me” SMS and subsequent telephonic follow-up become central. She was worried that when this does not occur, clients become overwhelmed by the changes and resultant needs associated with their disorders if not followed-up immediately.

(...) I feel worried that their disorder might change and they get lost in the system and then who does the follow-up, if we aren't there to do the follow-up for them? So it becomes a critical issue.

This adds to findings by Zagaria (2006) who found that, when lacking appropriate support, clients become overwhelmed when having to manage their own health and by the pressures of achieving therapy goals.

The SLP felt that the strategies and materials provided to the clients gave them an opportunity to comprehend and recall aims and rationales for treatments. She thought that even when these aims become obsolete because the disorders have changed, clients can go back to the information, realise that it is not sufficient anymore and know that they need to contact the SLP to solve their current problems. However, this is dependant on clients' level of health literacy, motivation and insight (Richards & Sayward, 2006; Moon et al., 1998).

The above perspective provides a reason why these strategies would be effective in the treatment of the disorders focused upon in this study, as well as in any other disorders treated in Speech-Language pathology. This provides a contrast to some SLPs views in phase 1 and 3, about the appropriateness of the combined strategies when treating urgent and life-threatening disorders (e.g. dysphagia, laryngectomy), as opposed to others (e.g. articulation and language disorders).

***Is the combination of the strategies usable in the intended environment and for the intended purpose? (SLPs' and clients' attitudes towards using the strategies in future)***

Overall, the SLP was enthusiastic when asked whether or not she felt that she would like to routinely use the combined strategies. She explained:

(...) I would definitely use the strategy if I had something set up here at the centre and say for instance they gave me this in a budget and they gave me the resources to be able to do it, then I would have done it.

However, she emphasised that she would have to set up a system for recording information that was not intrusive to the client and instead of having the “please call me” SMSes come to her personal mobile phone, have a computer system at the Centre that would receive SMSes (e.g. M-DFAQ

system by Ng'ambi, 2005). She explained that this is important as she works in a team setup and clients frequently have difficulties that have to be addressed by a team of experts. This emphasises the usefulness of the “please call me” SMS and telephonic follow up when clients are managed by various health professionals.

Though mostly positive about the combined strategies, both the couple and the SLP expressed some concerns with the “please call me” SMS. The client's wife explained that while she had access to her sister-in-law's mobile phone for emergencies, she felt uncomfortable having to ask her for it. This might have been exacerbated by the fact that she already relied so much on this family member. The SLP also emphasised that one does not know what the familial circumstances are, which is why caution needs to be exercised when assuming that clients can rely on family members' equipment in order to make use of the strategies. The SLP also explained that while the idea behind the combined strategies is appropriate, the way in which they are implemented may have to be reconsidered, because of the different resources available to clients from urban versus rural areas. As an improvement or alteration of the combined strategies, the SLP suggested video-recordings and recording on mobile phones, provided that clients have access to VCRs or DVD-players and good quality mobile phones. These tools were also proposed as effective strategies in the literature review (Santo et al., 2005; Weiss; 2007; Table 1).

### ***Do users need more training and guidance in order to use the strategies appropriately?***

The SLP emphasised that:

the clients (...) have got to become disciplined in doing their home programmes and I think that if they start at the early stage with these things (the strategies) and they are literally trained in the discipline of doing it (...)

Clients need to be disciplined about effectively using the strategies that are provided to them and this sometimes requires training. When given time and the resources, both the SLP and the couple may have no difficulties in implementing and utilising the combined strategies in future (Doak, Doak & Meade, 1996).

### ***Effects that the combination of these strategies have on structural or process quality (e.g. time saving, clinical workflow)***

The SLP explained that if the combined strategies are provided right at the beginning of the treatment process, difficulties may be dealt with more rapidly as clients have a chance to review the information and they can get into contact with the SLP. She added:

(...) then as time goes by and they start improving and spontaneous recovery happens then there won't be any difficulties or problems. Then we won't have to do it (provide strategies) this often, you won't have to do it every week, then you can do it sporadically over two weeks or three weeks.

Clients may have to attend fewer appointments, which saves both parties time and various costs. She further stated that the combined strategies were suitable for information review by other health professionals especially when clients are managed in teams, as all the information and contact details can be provided by the client. However, it would probably be more time-efficient for other health professionals to review clinical information from each client in point-form as can be found in each client's medical folder.

## **Conclusion**

In this case study, strategies that were used were counselling, illustrations, written information in point-form, an audio-recording, the option of a "please call me" SMS and telephonic follow-up. Management in this case was effective and the SLP had a positive experience when using the combined strategies for improving health literacy and recall of clinical information. One advantage of the combined strategies which stood out most in this case study was that the strategies and materials provided clients with an opportunity to comprehend and recall aims and rationales for treatments. Moreover, when these aims become obsolete in the event of regression or improvement of a disorder, clients can review the information, realise that it is not sufficient anymore and become conscious of their need to contact their SLP to solve current problems. Even though the SLP saw the value of the combined strategies, she had some concerns which would have to be addressed.

The SLP in this case study was noticeably more positive, motivated and enthusiastic about implementing the combined strategies in future compared to the therapists in the first and second case study. It was unclear whether this was due to the fact that she was younger and had spent less time practicing than the former SLPs, who were realistic about the uses of the combined strategies.

#### **4.4. Case Study Four (adult client with a voice disorder)**

##### **Background**

This client was a 58-year old woman who had been referred to the SLP at a tertiary hospital after being seen by an ENT. She presented with a hoarse voice as a result of being a smoker for many years, and vocal abuse and misuse. She was employed as a tea-lady at a major company and was living in a house with her teenage daughter. She was in possession of a CD/tape-player as well as a house telephone and she would occasionally use her daughter's mobile phone if needed. She described her literacy skills to be good but she admitted to having occasional difficulties when having to read complex text like that in medical forms/pamphlets and medication labels. She also explained that she occasionally had difficulties in learning about her or other family members' medical conditions because of difficulties in understanding medical written or verbal information. Her treating SLP has had 8 years of experience in the field and in working in public hospitals or clinics with respective client populations. She is a first language English speaker.

##### **First consultation**

The client appeared to be an enthusiastic and motivated individual especially as she recently saw her brother pass away as a result of throat cancer and she was determined to become healthy. A detailed voice assessment was conducted. Thereafter, the ENT's and the SLP's results were discussed. A sheet with therapy exercises was provided to the client together with written suggestions on how to preserve her voice. All this information together with her actually executing the exercises was recorded on a tape for her to take home. The written information was presented in big print with short sentences and clear wording. She was also sent home with the SLP's mobile phone number and a "please call me" code. The procedures on how to use the strategies were explained once more before she left the consultation. There was a period of six weeks between the first consultation and the client's next follow-up appointment. No "please call me" SMS was sent during the time between the first consultation and follow-up appointment.

##### **Follow-up appointment**

The SLP proceeded to ask the client what exercises she had been practicing and whether she could provide examples of how she had preserved her voice, which she was able to do. It was agreed by all

three parties (SLP, client and researcher) that there was a remarkable improvement in her voice quality. The SLP clarified the follow-up findings of the ENT and further explained to her that she needed to continue with the previous exercises and preserving her voice. It was also explained that this was not a “once-off” treatment but that she would have to be aware of preserving her voice for the rest of her life.

## **Evaluation and discussion of data gathered in phase three for case study four**

### ***Improvement of health literacy and recall of clinical information (long- and short-term)***

In the questionnaire, the SLP agreed that the combined strategies were effective in inducing compliance and behavioural change as the client had a chance to review details of information that was necessary for her to manage her own health. The client reported that even though she had understood everything once she had left the consultation for the first time, she felt the need to listen to the audio-recorded information frequently because it contained details to the written information provided for her. She explained:

Ja, jy weet ek het nou al die informasie op 'n papier gekry, maar dit is vir my baie beter om die tape aan te sit en te luister ja. (...) Die ekstra informasie wat daar nog by is (help) ja.<sup>12</sup>

This yet again concurs with Tattersal et al. (1994), who found that there are information details on an audio-recording that may be lacking in written materials or when having to recall verbal instructions.

It also became apparent that she initially did not understand why she had to see the SLP in addition to the ENT. She explained:

(...) Ek het nie eers verstaan nie hoekom ek van die dokter af en dan na julle moet kom nie om nou daaroor gesels oor my keel nie, maar later toe voel ek nou meer...nee dit is 'n goeie iets... Want van dat julle met my gesels het, het ek huis toe gegaan en ek het gesit in my kamer en ek het die papiere so gevat en geluister en ek het gedink...dit is 'n goeie iets (...).<sup>13</sup>

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<sup>12</sup> **Translation:** You know I got all this information on a piece of paper but it is better for me to put on the tape and listen to it. (...) The additional detail to information that is on the tape is helpful yes.

<sup>13</sup> **Translation:** First I did not understand why I had to come to you after I had seen the doctor, to talk about my throat. ..but later I felt...no this is something good. After I had spoken to you, I went home and I sat in my room and I took the written materials and I listened and I thought; this is something good.

After her first consultation she had gone home and reviewed all the materials while listening to the audio-recorded information which is when she realised how important this treatment was for her. This shows the importance of clients learning about the relevance of various health professionals in their treatment (Zarcadoolas et al., 2006). The importance of this aspect of client education was also discussed in section 3.2.

The client found that the combined strategies gave her the opportunity to manage her voice disorder on a long-term basis rather than just “once-off”. As a result of dedicating time, sitting down and following written instructions while listening to the tape, she may have felt more like she was doing a whole treatment session rather than just reading a sheet of written clinical information in point-form which could be less engaging after a period of time (Plimpton & Root, 1994) or it might not be appropriate to her learning style (e.g. she might prefer a range of audio, visual or pictorial materials) (Stone 1979; Hoffman & McKenna, 2006).

***Satisfaction related to the value that is placed on the strategies or the extent to which the participants found them to be helpful***

The client preferred listening to the tape rather than reading the written information because the tape contained a voice, which was also found by Tattersal et al. (1994), who established that clients particularly preferred an audio-recording to written materials, because it contains reassurance that might be lacking in written materials. This was also mentioned by the client in case study one who found listening to a voice reassuring, personal and human. The client added that the tape, together with the written information, assisted her in describing her disorder and treatment to people in her immediate environment which was also mentioned as an advantage by participants in case study three and in the literature review (Stockler et al., 1993). Even though the client did not feel the need to send a “please call me” SMS to the SLP because she did not have any difficulties, she did think that it was a reasonable tool to have in case she had a voice related problem. She explained:

(...) ek het baie bly gevoel toe julle vir my die nommer gegee het so as enige iets nou kom met my stem dat ek kan bel. Ek het dit werk toe gevat. (...) want baie keer as ek by die werk is dan slat my stem so toe...dan stuur hulle vir my dokter toe...<sup>14</sup>

This is where it becomes imperative that people in a client’s immediate environment can get into contact with the SLP in charge at low cost.

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<sup>14</sup> **Translation:** I was happy when you gave me that number because if something happens to my voice now, I can call. I took it to work (...) because often when I am at work, then my voice seizes completely and then they have to send me to the doctor...

The SLP explained that in the presence of adequate equipment, providing the combined strategies was culturally appropriate, user-friendly and useful because once the client had left the consultation, the information that she was taking with her was clear, accurate and complete and ready for review to improve understanding and recall of clinical information at any stage post-consultation. Kessels (2003) as well as Flocke and Stange (2004) also viewed this to be important for assuring clients' compliance to treatment. Furthermore, just like the SLP in case study three, this SLP felt that the combined strategies were appropriate to use in the management of voice disorders, laryngectomees and cleft lip and/or palate. She emphasised that irrespective of the disorders, clients presenting at her clinic all have low socioeconomic backgrounds and roughly the same education levels. Thus, the combined strategies would serve them all in maximising health literacy skills, recall and compliance. However, as most other SLP participants, she did have concerns about utilising the combined strategies when managing dysphagia as consequences resulting from misunderstandings can be severe (Chadwick et al., 2002; Cherney, 1994).

***Is the combination of the strategies usable in the intended environment and for the intended purpose? (SLPs' and clients' attitudes towards using the strategies in future)***

The SLP and the client agreed that the combined strategies were useful for people who have low health or general literacy skills and who reside in rural/impoverished areas when they do not have the financial means to come for frequent follow-ups or contact their SLP (Kagee, 2004). The SLP explained:

(...) they will use their last money because they are concerned about their health...so you can't come and waste their time. You need to give as much as you can especially for the people who live far (...) They need to leave feeling that it was worth that 60R or whatever that they gave out.

Health professionals have to make every effort to ensure that clients understand their treatment regimen and can manage their own health when they return home so that motivation and treatment compliance can be improved (Ley, 1982). This has also been mentioned by most therapists in this phase of the study as well as in focus groups discussions which confirms SLPs awareness of the importance of these variables.

In the questionnaire, the SLP agreed that the combined strategies were effective in assuring continued contact and service delivery post-consultation. However, she emphasised that messaging through the internet would be more appropriate after having heard about the M-DFAQ system (Ng'ambi, 2005). Like the SLP in case study two, this SLP was undecided about whether the

combined strategies really made a difference in this client's treatment because the client could read. However, the client's responses above, confirm that the combined strategies assisted her in various ways, which shows that these strategies are beneficial to clients regardless of their literacy skills. This also agrees with research findings by Weiss and Coyne (1997) and Yin et al. (2007), who found that most strategies lead to the improvement of knowledge about health and behaviour change, in both clients with limited literacy and those with good literacy skills.

The SLP raised two further points: (a) that clients might not have the insight to realise that they need to question certain aspects of therapy or acknowledge their need to contact the therapist for assistance, and (b) when clients have a problem, they usually consult someone in their community who they regard as being wise (e.g. a traditional healer or a community leader) which could ultimately result in the combined strategies being futile. The researcher and the SLP agreed that, should the combined strategies be implemented at an institution; it would allow people to become used to their presence and they might use a combination of strategies or just parts of them more readily and effectively. She also highlighted that it is important to understand that cultural influences are particularly strong in rural areas. Even with new technologies, people in rural areas might not have the means to access them or they might not be interested in utilising them (Zhang & Bennet, 2001). In this case, the SLP would have to investigate a client's needs and preferences (Hoffman & McKenna, 2006; Zhang & Bennet, 2001) after which a joint decision could be made on a strategy which allows for regular contact with the SLP and also maximises that client's health literacy, recall and resultant compliance to treatment.

***Do users need more training and guidance in order to use the strategies appropriately?***

When given time and the resources, both the SLP and the client may have no difficulties in implementing and utilising the combined strategies in future (Doak, Doak & Meade, 1996).

***Effects that the combination of these strategies have on structural or process quality (e.g. time saving, clinical workflow)***

As was found in all other case studies; when the combined strategies are provided right at the beginning of the treatment process, difficulties could be dealt with more rapidly as clients have a chance to review the information and they can get into contact with the SLP whenever they experience difficulties. Clients are equipped and thus more confident in managing their own health (Kubeck, 2002; Rosenstock, 2005).

## **Conclusion**

In this case study, strategies that were used were counselling, written information in point-form, an audio-recording and the option of a “please call me” SMS and telephonic follow-up. Management in this case was effective and the SLP and the client had a positive experience when using the combined strategies for improving health literacy and recall of clinical information. One SLP opinion that stood out from this discussion was that, irrespective of the presenting disorders, clients at one institution (included in this study) all have low socioeconomic backgrounds and similar education levels, which is why the combined strategies would serve them all in maximising health literacy skills, recall and compliance - and not just clients with selected disorders. The SLP did raise some concerns which would have to be addressed if the combined strategies were to be used in future. Once more, this SLP was noticeably more positive, motivated and enthusiastic about implementing the combined strategies in future compared to the therapists in the first and second case study. Yet again, it was not clear whether or not this was due to the fact that she was younger and had spent less time practicing than the former SLPs, who were realistic about the uses of the combined strategies.

### **4.5. Comparison of all four case studies**

Management of three out of the four case studies was effective and all clients received the same strategies. Various factors played a role in each particular case and participant SLPs drew diverse conclusions as to whether or not the combined strategies improved health literacy, recall of medical information and compliance with treatment. Firstly, clients in all four case studies listened to the audio-recorded information and were aided through being able to review the detailed conversation. Furthermore, clients in case studies one and two found listening to a voice more reassuring, personal and human compared to written information. These are important findings as much of the literature usually provided to clients goes unread (Plimpton & Root, 1994). The combined strategies allowed clients to take home information that was clear, accurate and complete and ready for review at any stage post-consultation. In most cases, providing the combined strategies was time well spent, especially when clients were at “high-risk” and had ready access to the equipment needed to utilise the strategies. Through access to the combined strategies, clients were equipped to confidently manage their (or their child’s) health, and simultaneously made responsible to take their (or their child’s) health into their own hands and educate people in their immediate environment.

Some SLPs indicated the cost-effectiveness of using the combined strategies in that if clients were to start using these strategies early in their treatment process; recovery could be quickened as clients can review information in their own time and through regular telephonic contact, clients can be assisted continuously, not just at follow-up appointments. This would also save government funds and SLPs' time. In addition, the strategies would not require expensive equipment to be bought. For example, when using something like the M-DFAQ system (Ng'ambi, 2005); most hospitals/clinics have access to the internet and generally people have access to phones and mobile phones. Furthermore, CDs/tapes can be bought in bulk. The only equipment that would initially need the investment of a small sum is a portable CD burner and audio-recorder. However, this is equipment which should be useful for many other tasks (meetings etc.) in hospitals/clinics too.

Various issues were raised. The audio-recording may not be of any benefit to other health professionals who come into contact with the client. It would be easiest for them to access clients' clinical notes or visual aids (i.e. DVD/video of a session). However, the client may be able to effectively explain their situation and previous recommendations as they have had repeated opportunities to review the information. Consequently, time is saved, a resource that is scarce in the clinical environment. In the literature review, the researcher presupposed that SLPs may prefer access to various strategies depending on the needs of the client and that they might have individual preferences over certain strategies/technologies depending on how easily these could be integrated into their practice. It was found that SLPs would need time to develop the best equipment and procedure (through clinical trial and error as well as systematic research) so that they could make informed and effective decisions for when and how to use these strategies so that administering them does not become an added burden. SLPs would also need additional funds to buy equipment, which is difficult in government hospitals/clinics.

All the effort would be a waste of time, if interpreters are not readily available both at times of audio-recordings and during telephonic follow-up. Furthermore, SLPs made it clear that the combined strategies are not a blanket technique for all clients. Clients (a) would need to have access and experience in using the equipment needed to utilise the combined strategies and (b) be insightful, motivated and have enough problem-solving skills to effectively use the strategies. A client's stage of recovery and resulting coping skills as well as cultural influences and familial circumstances are also variables that have to be considered. These former variables are partly the reason why the outcomes of client compliance in case study one differed from those in case studies two, three and four.

When considering all participants' opinions, it was seen that the general feeling of clients about the value of the combined strategies, was positive. However, it seemed that clients would be satisfied with any strategy which is novel and makes them feel confident in managing their own (or their child's) health. SLPs were generally positive about the combined strategies. However, SLPs of case study three and four were noticeably more positive, motivated and enthusiastic about implementing the combined strategies in future compared to the therapists in the first and second case study. It was not clear whether this was due to the fact that they were younger and had spent less time practicing than the former SLPs, who proceeded to be realistic about the uses of the combined strategies.

## **Conclusion**

The combined strategies (audio-recorded information, "please call me" SMS and telephonic follow-up) are strategies which proved to be of assistance to all four cases under study. One important advantage of the combined strategies, was that the strategies and materials do not only provide clients with an opportunity to comprehend and recall aims and rationales for treatments but when these aims become obsolete in the event where disorders have changed, clients can go back to the information, see its irrelevance, and realise their need to consult their SLP. However, one important question that stood out was whether or not this specific combination of strategies would perhaps be more effective with disorders that are less severe, complex and acute. According to one SLP; irrespective of what disorders clients at one of the institutions present with, they all have low socioeconomic backgrounds and roughly the same education levels. Thus, the combined strategies would serve them all in optimising health literacy skills, recall and compliance and not just clients with selective disorders. Where viewed to be appropriate, the combined strategies should be provided to most clients who seek Speech-Language Pathology treatment, especially those with low literacy skills and who do not have the financial means to attend frequent therapy sessions or contact their SLP telephonically. It is important that clients are equipped with enough tools, especially at initial stages of recovery in order to feel capable of managing their (or their child's) health and know that they can easily contact the SLP when in need.

## **Chapter 5: Implications and conclusions**

### **5.1. Implications of this study**

The key points that were extracted from phase 1 and 3 are presented below. Subsequently a preliminary framework is presented, incorporating the clinical implications of this study. This aims to serve as a decision framework for SLPs who want to maximise health literacy, recall and compliance in their clients.

Firstly, it was found that clients' motivation and sense of role and responsibility in their own healthcare (which is also linked to insight) are the most vital characteristics that a client needs to comply with treatment. Providing that the client is motivated and insightful, and they are equipped with strategies; it may improve the chances that they will be able to take charge of their (or their child's) healthcare. This finding concurs with Richards and Sayward (2006) who stated that without motivation and insight, any strategy or treatment regimen will be unsuccessful. This is also why some SLPs in this study were aware that the strategies might not be a universal technique to use with any client. An implication of this finding is that SLPs need to be aware that motivation and insight may impact on compliance and treatment outcomes with or without strategies and therefore should also consider interventions to improve these.

Secondly, it was found that a caring and supportive therapist is necessary for clients to feel comfortable. It would be inappropriate to expect that the combined strategies could solely assure that health literacy and recall are maximised. Technology can support and assist clients but SLPs' personality and skills are also necessary when improving client compliance, health literacy and recall. The impact that dynamics in client-provider relationships have on the success of client outcomes is not to be underestimated (Cilliers, 2005; Kagee, 2004; Kubeck, 2002; Rosenstock, 2005).

Thirdly, it was found that three out of four cases did not make use of the opportunity to be in regular contact with the SLP. One reason may be that clients are not used to initiating regular contact with their SLP. With time, encouragement and practice, more regular contact between SLPs and clients could be improved (Osborne, 2008b) which is an important element necessary for crisis-management, adequate follow-up and therapy to be guided and updated especially when the status of disorders changes. At the same time it was found that clients have to be insightful enough to realise

when they need assistance and make that contact so that no time is wasted and disorders do not deteriorate. Thus, when a SLP identifies a client who is at “high-risk” for non-compliance, they should initially contact the client to encourage recall and problem-solving and at the same time teach the client to initiate contact. By knowing that clients can get into contact with their health professional, their anxieties may be eased considerably (Osborne, 2008b).

Furthermore, it was found that SLPs need to acknowledge that any strategy which makes clients feel confident because they are equipped and thus empowered to manage their (or their child’s) health is vital when wanting to assure continued service delivery and success in treatment (Moon et al., 1998). In addition, clients who are used to using the media that make up the combined strategies on a daily basis, would need less assistance in understanding how to use them but rather effectively and appropriately utilising them to manage their own health for which they need to be insightful, motivated and have adequate problem-solving skills. SLPs further need to be aware of this.

Strategies and materials do not only provide clients with an opportunity to comprehend and recall aims and rationales for treatments but when these aims become obsolete in the event where disorders have changed, clients can go back to the information, realise that it is not sufficient anymore and recognise their need to contact their SLP to solve current problems. This specific combination of strategies would be more effective with disorders that are less severe and medically complex. These would be for example voice disorders as opposed to dysphagia which is less predictable, and hands-on assistance from experienced professionals is needed. However, the “please call me” function and telephonic follow-up could serve as a strategy here. The cost effectiveness of the strategy using “please call me” SMS and telephonic follow-up is also relatively high.

These combined strategies might not only have different functions and possibly different outcomes in different disorders but they also might have different outcomes at different stages of a client’s recovery. Where viewed to be appropriate, the strategies should be *adapted* or provided *as they have been proposed*, to most clients who seek Speech-Language Pathology treatment for any disorder, especially those with low literacy skills and who do not have the financial means to attend frequent therapy sessions or contact their SLP telephonically.

Even though all SLPs saw the value of the combined strategies, younger therapists were noticeably more positive and enthusiastic about implementing the combined strategies in future compared to therapists who had many years of experience. It was difficult to decide whether or not this was due to the fact that the former SLPs were younger and had spent less time practicing than the latter SLPs, who were realistic about the uses of the combined strategies. Therapists who have been in the field for many years have settled on what they perceive to be most appropriate for information exchange in practice and they have had much experience with client's lack of adherence to treatment regimes, despite their effort to assist clients in complying. On the other hand, it might be that younger therapists still like to experiment with various avenues of information exchange with their clients, which could be a reason for their enthusiasm towards the combined strategies. This adds information to the impact that professionals' individual characteristics can have on the way that they provide clients with information or strategies for information exchange. Depending on how reflective and involved the professional is; the appropriateness of health information and effective communication will be impacted (Katz & Scarpati, 1995).

Coulter and Ellins (2007) advised that despite evidence of the benefit of innovations to advance health literacy, barriers include a lack of skills and knowledge on the clinicians' part and there are concerns about time and resource pressures in the clinical setting. It is found that given time and the resources, SLPs and clients would be able to utilise the combined strategies or parts of them to assist in health literacy and client recall without any difficulties in future. In addition, SLPs would have to investigate a clients' stage of recovery (and resultant coping skills), personal situations, learning styles and ways of thinking and problem-solving when wanting to maximise information uptake (Fitzgerald Miller, 1992; Hoffman & McKenna, 2006; Stone, 1979). Subsequently, both parties could jointly decide on a strategy which allows for regular contact with the SLP and also maximises that client's health literacy and recall.

The impact of low health or general literacy skills, socio-economic status, clinical variables, access to services as well as trauma and anxiety have been identified in this study and by various authors as obstacles to compliance (Fitzgerald Miller, 1992; Flocke & Stange, 2004; Hester & Benitez-McCrary, 2006; Kagee, 2004; Louw et al., 2006). These obstacles need to be addressed at all times so that clients can be assisted in managing their health. Clients need to be attentive, confident and fully comprehend what is being discussed during consultations in order for them to stay motivated and be able to contribute to managing their own health; findings which concur with

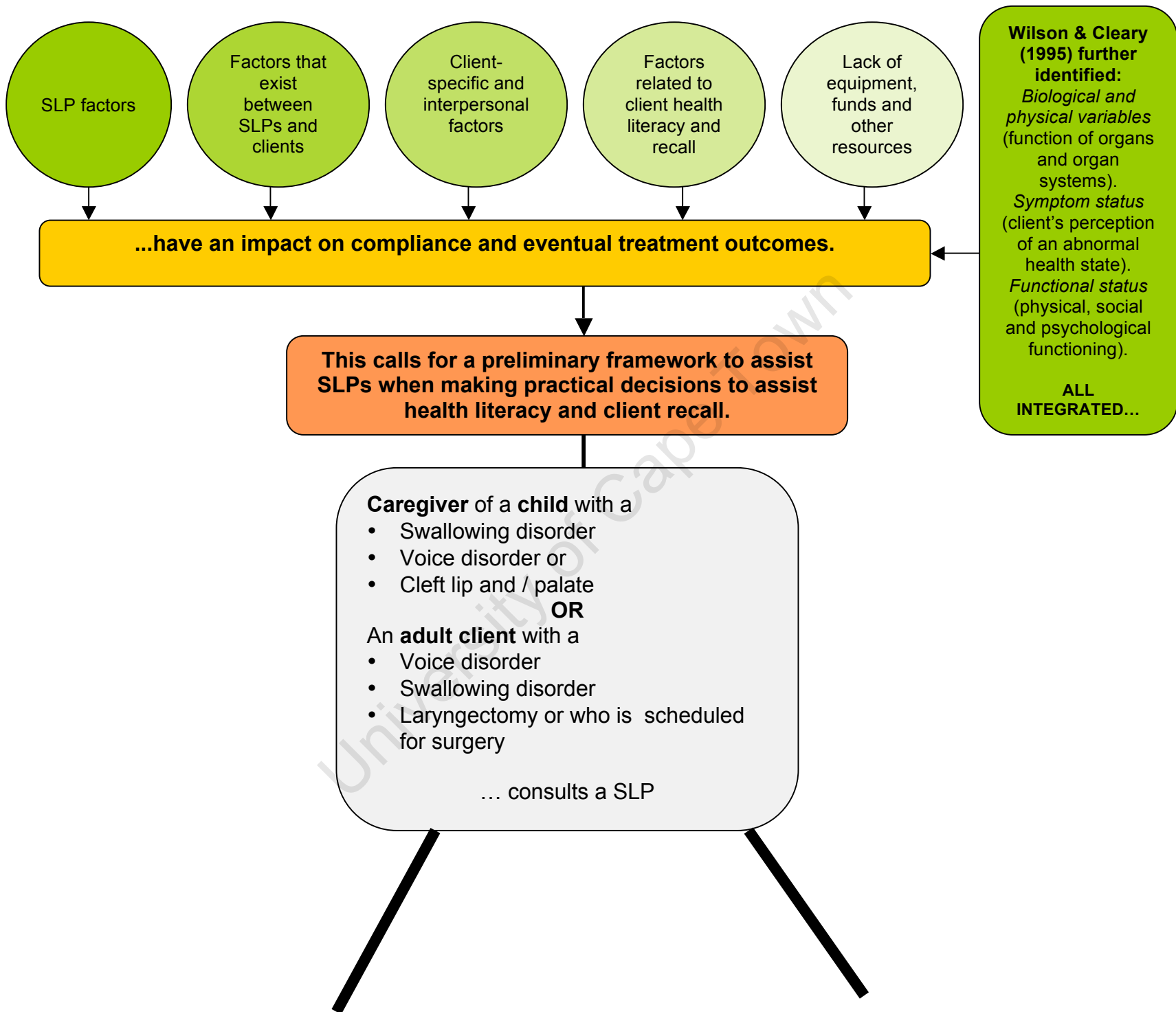
findings by Kubeck (2002) and Rosenstock (2005). This is also where SLPs roles in prevention and promotion become central to their quest for assisting clients in compliance with treatment.

Almost all the interventions that aim to improve compliance are complex (Kagee, 2004; McDonald et al., 2002). There is no one solution or universal tool for maximising health literacy and recall in the presence of various factors that impact the utilisation of the combined strategies and compliance. In addition to strategies that are used to facilitate understanding and recall of information during consultations (e.g. through the “teach-back” method), the combined strategies can be of assistance after the client has attended an appointment. However, there are various obstacles (including the need for and issues concerning interpreters) that must be addressed. It depends on each client and their treating SLP, which aspect of the combined strategies they see fit to use. The cycle of low health literacy and educational levels, poor income and health and the inaccessibility to information technology can be broken if information technology is brought to those who are underserved (Coulter, 1999; Eysenbach, 2000).

When considering the findings of this exploratory study, it was felt appropriate to work towards a preliminary framework that could serve as a decision tree for SLPs who want to maximise health literacy, recall and compliance in clients. In the literature review, a model by Wilson and Cleary (1995) was briefly introduced (section 1.5. under resolutions). The researcher evaluated this model together with similar suggestions by Bunning (2004) who also developed a concept with specific focus on the most appropriate course for intervention processes with clients in Speech-Language Pathology. It was found that what is lacking in this study is what Wilson and Cleary (1995) identified as physical and psychological variables (i.e. biological and physical variables, symptom and functional status). Even though clients’ emotional wellbeing was mentioned as a variable in this study, biological and physical variables as well as the effect of a client’s symptom status did not feature as much in the results of this study. On the other hand, while the models by Wilson and Cleary (1995) and Bunning (2004) included most key findings and points that were identified in this study, they overlooked some very important additional variables. These variables included the role of caregivers; health literacy skills and client recall; lack of equipment, funds and other resources; dynamics in client-professional relationships as well as the role of characteristics of the health professional in client compliance. Thus, when gathering all these findings, a comprehensive but preliminary framework for clinical practice was developed. This framework is preliminary because it only focuses on the disorders and settings under study. Future research which explores the

combined strategies on other disorders in different settings would assist in making this framework more holistic and complete. The following Figure presents this framework and the relevance of the combined strategies proposed in this study. This framework as presented in Figure six can be distributed independently as a resource tool for SLPs (please refer to envelope inside back cover of this report).

University of Cape Town



SLP factors

Factors that exist between SLPs and clients

Client-specific and interpersonal factors

Factors related to client health literacy and recall

Lack of equipment, funds and other resources

...have an impact on compliance and eventual treatment outcomes.

**Wilson & Cleary (1995) further identified:**

*Biological and physical variables* (function of organs and organ systems).

*Symptom status* (client's perception of an abnormal health state).

*Functional status* (physical, social and psychological functioning).

**ALL INTEGRATED...**

**This calls for a preliminary framework to assist SLPs when making practical decisions to assist health literacy and client recall.**

**Caregiver of a child with a**

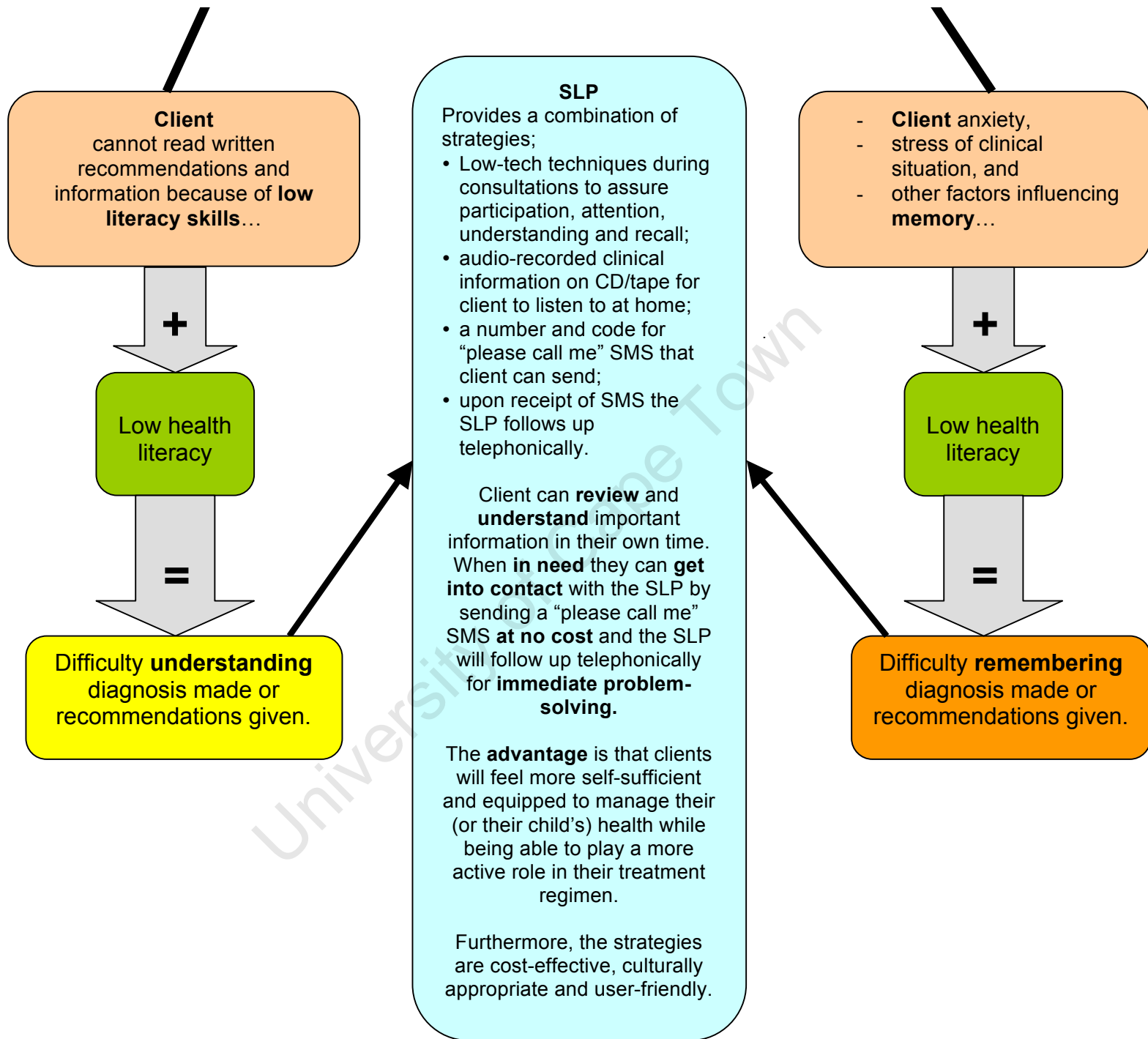
- Swallowing disorder
- Voice disorder or
- Cleft lip and / palate

**OR**

**An adult client with a**

- Voice disorder
- Swallowing disorder
- Laryngectomy or who is scheduled for surgery

... consults a SLP



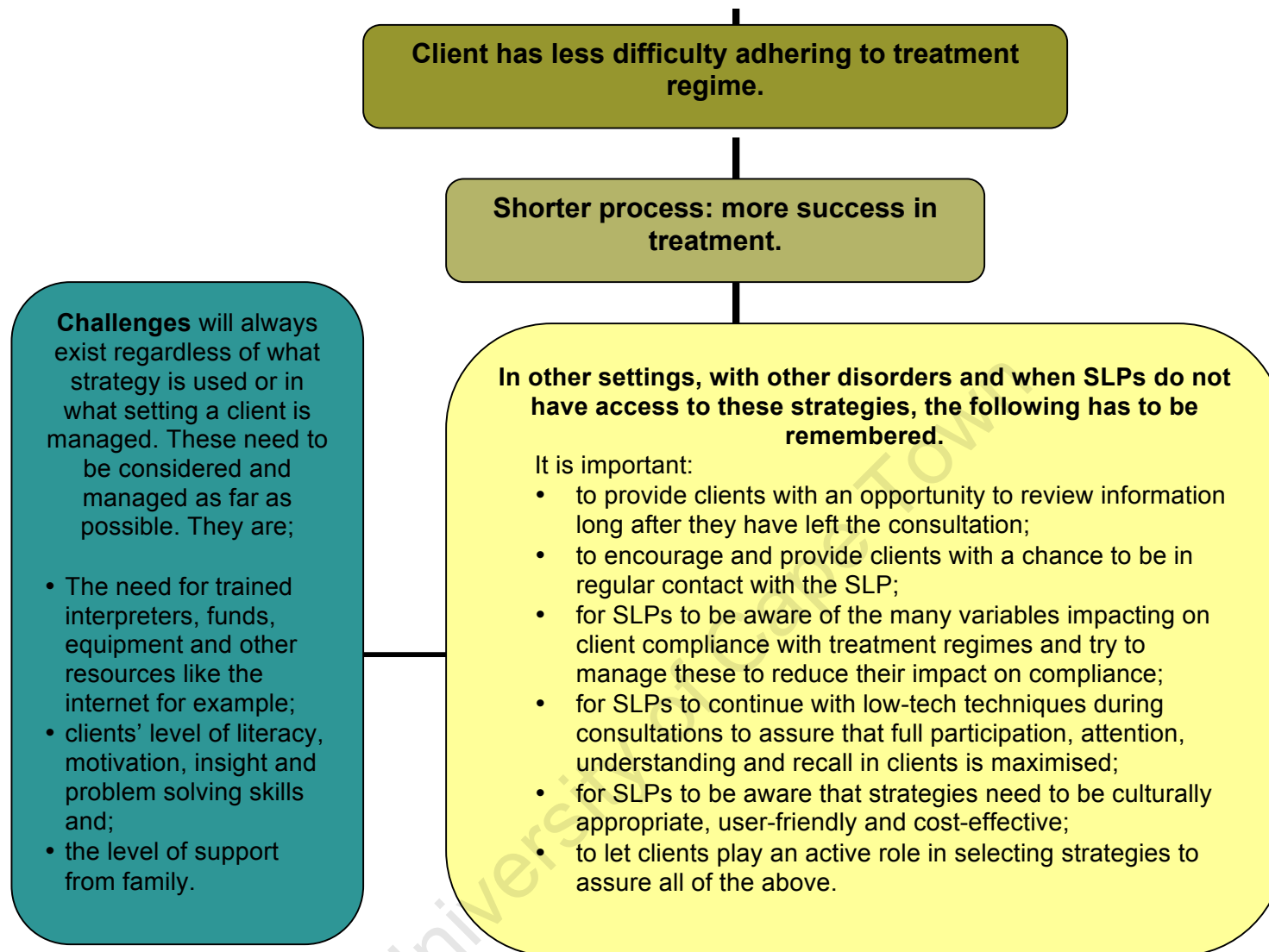


Figure 6. Preliminary framework for clinical practice using the combined strategies

## **5.2. Limitations of this study**

The researcher used non-probability sampling which does not allow for generalising data. Furthermore, due to limited sample size and focus on specific disorders and settings, findings could not be generalised and applied to the greater field of Speech-Language Pathology in South Africa. However, this was an exploratory study which is typically done to (a) satisfy the researcher's interest and desire to gain a better understanding, (b) test the viability of undertaking a more extensive study, (c) develop methods to be used in a subsequent study, (d) establish priorities for future research, and (e) develop new hypotheses with reference to an existing phenomenon. Therefore, the findings in this study served to generate richness of data to develop ideas or hypotheses, not facts that were to be generalised to a larger population or other settings.

The long-term effectiveness of the combined strategies was not explored because of time constraints and thus it is unknown at this stage. In an ideal research scenario, these strategies should have been used with clients right through their treatment process. In addition to the long-term effectiveness, this would have provided findings about whether or not the combined strategies have different functions or outcomes at different stages of a clients' treatment.

It was shown that the combined strategies were of assistance to the four cases under study. However, due to the absence of finances and equipment which would have allowed for the combined strategies to be easily adopted into hospitals and clinics, these participants would not benefit from using the strategies after the completion of this research. With appropriate finance and resources, these strategies could be made available to clients in various settings.

Due to the limited sample size, only one caregiver was included in this study. Very little research has focussed on caregivers with regards to health literacy and recall. Even though a caregiver of a child was included in this study, more caregivers especially those who are primarily responsible for adults should be included in a future project so that more insight can be provided into the needs of these individuals in Speech-Language Pathology management.

Another procedure that could have been conducted was to perform a quiz with clients right after the consultation and then again before the next follow-up appointment to generate an additional branch of findings that would show (a) how much information the client initially understood and recalled and (b) how much information they could recall and describe after having used the strategies at

home. This would have generated an additional objective view of whether or not the combined strategies assisted in understanding and recall when the client first left the consultation to manage their disorder at home. A control group to compare one group with strategies to a group that did not have access to additional strategies also could also have been helpful here. However, it was established in the literature review that clients typically struggle with understanding information and recall when they do not have strategies to assist them. Therefore, it was decided that no control group would be necessary because the findings would typically be similar to those in the literature review. Furthermore, the purpose of this study was to explore the outcomes of the strategies that were to maximise health literacy and recall to find a solution to the issues that occur when clients do not have access to strategies to assist them in managing their (or their child's) health and it would have been unethical to withhold a chance to be assisted in health literacy and recall from clients.

### **5.3. Recommendations for future research**

In the presence of the above limitations of this study, some suggestions for future research are as follows:

A larger more representative sample could be investigated in order to be able to generalise findings. Probability sampling would be used which is an efficient method for selecting a sample that would adequately reflect variations that exist in the population (Babbie & Mouton, 2004). This also means that more caregivers of adults and children would be included in the sample in addition to clients who have different disorders and who come to various healthcare settings in different parts of the country. Clinical implications could thus be developed to design a framework for clinical practice that would cover the entire Speech-Language Pathology profession.

Should a similar methodology be used in a future study, an assessment of clients' knowledge before they leave consultations and when they return for follow-up appointments should be conducted. This would generate an additional objective view of whether or not the combined strategies assisted in understanding and recall of information which the client needed to appropriately manage their health. Further research should be directed towards investigating the long-term effectiveness of the combined strategies at different stages of a client's recovery. This would provide findings about whether or not the combined strategies have different functions or outcomes at different stages of a clients' rehabilitation. Once this is attempted, the strategies' sustainability and details on the actual

cost-effectiveness would be better determined so that a plan for funding and equipment (supported by research) could be established.

Last but not least, clients from high socioeconomic backgrounds with insight and literacy skills may be affected by some of the variables to compliance that were identified in this study and in earlier literature (Glassman, 2007; Moon et al., 1998). These clients would be just as overwhelmed, anxious and stressed by clinical environments and having to deal with various health professionals. They may also have different priorities when it comes to healthcare and they need to be just as motivated and assertive to succeed in treatment. Strategies to assist in understanding and recall of information are important for every client regardless of their level of literacy or socioeconomic status. Participants with good health literacy skills should be included in future studies to identify their needs and issues that play a role in their compliance. Further research topics could include (a) whether or not the issues that these clients experience are similar or different to those of clients with low health literacy skills and (b) which strategies could be of assistance to their compliance with Speech-Language Pathology treatments.

#### **5.4. Conclusion**

The aim of this study was to (a) explore health literacy and information recall/memory of clients receiving Speech-Language Pathology treatment in public hospitals/community rehabilitation clinics in Cape Town, and (b) to explore ways of maximising health literacy and client recall/memory of clinical information in clients with dysphagia, voice disorders (including laryngectomies) and cleft lip and/or palate. In the presence of very little prior research on this topic in Speech-Language Pathology, this study was set out to (1) explore SLPs' and clients' views on health literacy and client recall/memory and how these might be maximised, (2) trial the use of technology/strategies, and (3) evaluate the outcomes of the technology/strategies employed from both the SLP's and client's perspective. This study intended to provide insight and contribute to information about ways in which SLPs could overcome issues of health literacy skills and client recall/memory so that treatment effectiveness and efficiency could be improved.

There were various factors which played a role in clients' compliance with treatment regimes. These were related specifically to the client, the SLP, health literacy and recall, factors that existed between SLPs and clients as well as the clinical environment. SLPs typically utilised various

strategies (mostly low tech) to overcome some of the issues around health literacy and client recall/memory of clinical information during consultations. However, these strategies are not always sufficient to address the needs of clients who have low health and general literacy skills or who come from impoverished or rural areas.

This study provided insight into various strategies that are available for information exchange. While considering the advantages and disadvantages of these strategies, the researcher proposed a combination of strategies to address specific issues around health literacy and client recall/memory of clinical information. The combined strategies (audio-recorded information, “please call me” SMS and telephonic follow-up) proved to be of assistance to all four cases under study. However, it became clear that there is no one solution or universal tool for maximising health literacy and recall. Clients (a) would need to have access and experience in using the equipment needed to utilise the combined strategies (b) be insightful, motivated and have adequate problem-solving skills to effectively use the strategies and (c) one would have to consider cultural influences as well as familial circumstances if one wants the strategies to be effectual and utilised for their actual purpose. Furthermore, SLPs need time (to develop appropriate procedures) and finances to make the most out of the benefits of the combined strategies in future.

The need for further research was indicated to evaluate the long-term effectiveness of the combined strategies with a range of disorders in various settings across the country and at different stages of a client’s rehabilitation. Future challenges for SLPs will be to effectively manage barriers such as clients’ varying levels of literacy, motivation, insight and problem-solving skills; the lack of support from families; the need for trained interpreters as well as the lack of funds and resources. Ultimately, it depends on individual therapists themselves, whether or not they explore strategies for information exchange in order to maximise health literacy, recall and general client compliance, through all available means.

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## **Appendix A: Phase One; Procedures and Schedule for Discussions with Experts in Information Technology.**

Each expert was welcomed and thanked for providing their expertise to this study. They were then reminded about the following:

- In order to record exactly what was discussed, a tape recorder would be used. This tape would only be listened to by the research team.
- Their details would be kept confidential at all times.
- This entire process was not expected to take more than 45 min.
- A copy of the final research report would be available should they be interested to read it.

A background to the study was given. Important concepts were clarified and rationales were provided. The main question to start discussions followed.

- What could we use in the case where clients cannot necessarily read (so we cannot give them complex written materials) but we would like them to remember and understand our recommendations.

At the same time these strategies need to be easy to use, cheap, and culturally appropriate. It needs to fit into a low socioeconomic household and be time and resource efficient for clinicians.

**Appendix B: Table 1. Suggestions generated by experts in information technology**

Media	Descriptions	How this medium can be adapted to be utilised in Speech-Language Pathology services
<p><i>Mobile Dynamic Frequently Asked Questions (M-DFAQ) system by Ng'ambi (2005).</i></p>	<p>This is an internet-based SMS service. Users can send a SMS to a website at low cost (i.e. 1 or 2 cents). The message is displayed on this site and the intended recipient is able access it or reply by SMS at no cost to the individual.</p>	<p>A client could send an enquiry or an SLP could send a reminder to a client. These interactions are client-specific, clients can be reminded of important recommendations and feedback or clarification can be provided. The SLP could be alerted to new messages. Thus, no unnecessary time is spent by having to frequently check the site for messages.</p>
<p><i>Short video clips for personal computers (PCs) or mobile phones with Multimedia Messaging Service (MMS) function</i></p>	<p>Short video clips can be uploaded on a PC using a Web Cam, digital camera or USB video capture device. They can be stored as files in a library and burnt on a CD or downloaded on mobile phones via wireless facilities such as infrared, Bluetooth or MMS.</p>	<p>SLPs could video record the consultation and recommendations in any language (using an interpreter) on their PCs. At the end of the consultation this clip is sent from a PC directly to the client's phone or it is burnt on a CD. The client can view this clip on their phone, PC or DVD-player whenever needed. Information is client-specific, it can be shared with family and reviewed whenever needed and it is a reasonable option for clients with limited literacy skills.</p>
<p><i>Record a message via a digital audiorecorder on a PC and burning it on a CD</i></p>	<p>Short audio recordings can be burnt from a PC onto a CD and can be listened to via CD-player.</p>	<p>SLPs could burn audio-recorded information of the consultation and recommendations in any language (using an interpreter) on a CD for the client to listen to at home. The client can listen to this clip whenever needed. Information is client-specific, it can be shared with family and it is a reasonable option for clients with limited literacy skills.</p>
<p><i>Voice-file recorded via digital audio-recorder sent straight to the mail box of a mobile phone via the internet</i></p>	<p>An audio clip is sent via internet straight to the mailbox of a mobile phone. It can then be listened to by choosing the voicemail option on the mobile phone and selecting that message. Alternatively, the message can also just be spoken onto the voicemail of a client's mobile phone</p>	<p>SLPs can record an audio clip of the consultation and the recommendations and then send this clip via internet to a client's mobile phone. Alternatively, the SLP can also just contact and leave a message of reminders on a client's mobile phone. Information is client-specific, it can be reviewed and shared with family and it is a reasonable option for clients with limited literacy skills.</p>

<p><b><i>Device based on the idea of the i-Pod</i></b></p>	<p>A device like an i-Pod with a USB switch could be adapted to a more standard device for just audio-recording and feedback. Files could be uploaded from a PC and listened to via this device.</p>	<p>SLPs could audio record the consultation and recommendations in any language (using an interpreter) on their PCs via a digital audio recorder. At the end of the consultation this clip is downloaded on this special device via the USB port. The client can take it home and listen to it whenever needed. When therapy is completed this device can be recovered for use by another client. This device is sensible for clients who have no CD-DVD-player or mobile phone facilities. Information is client-specific and it can be updated by a SLP whenever needed. It can be reviewed and shared with family and it is a reasonable option for clients with limited literacy skills.</p>
<p><b><i>Reminder functions on mobile phones</i></b></p>	<p>Most mobile phones have a reminder option where reminders can be set for a specific time and date. An alarm is set off and the reminder is displayed automatically on the screen of the mobile phone.</p>	<p>SLPs could save important recommendations as a reminder on a client's mobile phone. These reminders will then aid the client in remembering and ultimately following these important recommendations. Information is client-specific; it can be shared with family and reviewed whenever needed.</p>
<p><b><i>Reminders for clients based on the idea of a call centre</i></b></p>	<p>This option requires a human resource. After a consultation, recommendations are recorded on a system designed for downloading clients' profiles and clinical notes. Each day different profiles of clients, who need a reminder, will appear on a PC screen. An employee will then contact these individuals and remind them about their recommendations and other important clinical information.</p>	<p>After a consultation, SLPs record recommendations on a system designed for downloading clients' profiles and clinical notes. These follow-up calls could assist clients in remembering vital recommendations and it allows for exchange of immediate feedback.</p>

## **Appendix C: Phase Two; Informal Health Literacy screening tool adapted from Chew et al. (2004) and Yin et al (2007).**

Chew et al. (2004) developed their health literacy screening tool based on six themes. These were (1) navigating the health care system, (2) completing medical forms, (3) following medication instructions, (4) interacting with health professionals, (5) reading appointment cards, and (6) coping mechanisms for low general literacy skills. These six themes guided the development of the screening questions below. In order to prevent participants from underreporting difficulties, the researchers also phrased questions to ask patients “how often” they had a problem or “how confident” they were in each of the six themes rather than asking “if” they had a problem. Finally sixteen questions were developed, pilot tested, and revised to increase clarity.

- 1) How often are appointment slips written in a way that is easy to read and understand?
- 2) How often are medical forms written in a way that is easy to read and understand?
- 3) How often are medication labels written in a way that is easy to read and understand?
- 4) How often are patient educational materials written in a way that is easy to read and understand?
- 5) How often are hospital or clinic signs difficult to understand?
- 6) How often are appointment slips difficult to understand?
- 7) How often are medical forms difficult to understand and fill out?
- 8) How often are directions on medication bottles difficult to understand?
- 9) How often do you have difficulty understand written information your health care provider (like a doctor, nurse, nurse practitioner) gives you?
- 10) How often do you have problems getting to your clinic appointments at the right time because of difficulty understanding written instructions?
- 11) How often do you have problems completing medical forms because of difficulty understanding the instructions?
- 12) How often do you have problems learning about your medical condition because of difficulty understanding written information?
- 13) How often are you unsure on how to take your medication(s) correctly because of problems understanding written instructions on the bottle label?
- 14) How confident are you filling out medical forms by yourself?
- 15) How confident do you feel you are able to follow the instructions on the label of a medication bottle?
- 16) How often do you have someone (like a family member, friend, hospital/clinic worker, or caregiver) help you read hospital materials?

## The screening tool used in this study:

1) How often are medical forms and pamphlets written in a way that is difficult for you to read and understand?

**Always**                      **Often**                      **Sometimes**                      **Occasionally**                      **Never**

2) How often are medication labels written in a way that is difficult for you to read and understand?

**Always**                      **Often**                      **Sometimes**                      **Occasionally**                      **Never**

3) How often are medical forms difficult for you to understand and fill out?

**Always**                      **Often**                      **Sometimes**                      **Occasionally**                      **Never**

4) How often are written recommendations for therapy/treatment difficult for you to understand?

**Always**                      **Often**                      **Sometimes**                      **Occasionally**                      **Never**

5) How often are verbal recommendations for therapy/treatment difficult for you to understand?

**Always**                      **Often**                      **Sometimes**                      **Occasionally**                      **Never**

6) How often do you have problems getting to your clinic appointments at the right time because of difficulty understanding written instructions about when and why you must come to the clinic?

**Always**                      **Often**                      **Sometimes**                      **Occasionally**                      **Never**

7) How often do you have problems learning about your (or your child's) medical condition because of difficulty understanding written or verbal information?

**Always**                      **Often**                      **Sometimes**                      **Occasionally**                      **Never**

8) How often do you need someone (like a family member, friend, hospital/clinic worker, or caregiver) to help you read and understand hospital materials?

**Always**                      **Often**                      **Sometimes**                      **Occasionally**                      **Never**

## Appendix D: Phase One; Consent Form for SLPs (focus groups)



UNIVERSITY OF CAPE TOWN

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of Health & Rehabilitation Sciences  
**Faculty of Health Sciences**

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Occupational Therapy · Physiotherapy  
Old Main Building · Groote Schuur Hospital · Observatory · 7925  
Telephone: + 27 21 406 6401  
Fax: + 27 21 406 6323

Dear Sir/Madam,

Re: Participating in research project at the University of Cape Town

I am a Master's student in the Department of Communication Sciences and Disorders at the University of Cape Town. In order for me to complete my degree, it is required that I conduct a research report. The research topic that I have selected aims to (a) explore health literacy and information recall/memory of clients, receiving Speech-Language Pathology treatment in a South African public healthcare facility (b) to explore ways of maximising health literacy and client recall/memory of clinical information in this population.

You are hereby invited to join a focus group, where you will have a chance to share (a) your views on issues around health literacy and client recall/memory of clinical information and (b) the possible impact these elements may have on the success of treatment. Additionally, information about strategies that might be used to improve health literacy and client recall/memory of recommendations will be discussed. Suggestions for the proposed study will be welcomed.

There are no risks associated with this research project. The results of this study may help SLPs and other researchers get a better understanding of what barriers exist when it comes to clients' understanding and recall/memory of clinical information. Results may also provide us with more insight into what can be done to improve clients' understanding and recall/memory of clinical information.

The focus group will take place at a time judged to be appropriate for most of the participants. In order to record exactly what is discussed in the focus group, a tape recorder will be used. This tape will only be listened to by the research team. Your details will be kept confidential at all times. However, I cannot *guarantee* confidentiality as it is possible that some participants may share what was discussed outside of the group. This is why I ask you kindly to respect fellow participants' confidentiality at all times.

This entire process is not expected to take more than 1 hour 30 minutes. Refreshments will be provided. A copy of the final research report will be available should you be interested to read it.

You may withdraw from participating in this study at any time, without having to give a reason for doing so.

Please be advised that once this study is completed, I will hold a talk about the outcomes of this study. All participants will be invited and there are CPD points to be had, should you decide to attend this talk.

I thank you for your time and your consideration of this matter.

Yours faithfully,

Friderike Schmidt von Wühlisch

*Should you have any questions, please do not hesitate to contact me on 076 902 2803 or my supervisor Michelle Pascoe on 083 379 8746 / 021 406 6043.*

*Should you have any queries about your rights and welfare as a research participant, please feel free to contact Prof Marc Blockman, Chairperson - Human Research Ethics Committee, 021 406 6496.*

---

**RETURN SLIP:**

**Biographical Details** *(for purpose of overview of participants' profiles)*

**Name:** .....

**Occupation & Place of practice:** .....

**Qualification:** .....

**Years of practice in public tertiary healthcare** .....

**Most experience in** ..... **(disorders)**

**Contact details:** .....

I, \_\_\_\_\_ *(full name in print)* understand my rights as a research participant and I voluntarily consent to participating in this study. I understand what this study is about, my role in it and how and why it is being done. I have received a copy of this consent form.

\_\_\_\_\_  
Signature of participant

\_\_\_\_\_  
Date

## Appendix E: Phase One; English, isiXhosa and Afrikaans consent forms for past-clients/their caregivers (focus groups)



UNIVERSITY OF CAPE TOWN

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of Health & Rehabilitation Sciences  
**Faculty of Health Sciences**

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Occupational Therapy · Physiotherapy  
Old Main Building · Groote Schuur Hospital · Observatory · 7925  
Telephone: + 27 21 406 6401  
Fax: + 27 21 406 6323

Dear Sir/Madam,

Re: Participating in research project at the University of Cape Town

I am a Master's student in the Department of Communication Sciences and Disorders at the University of Cape Town. In order for me to complete my degree, I must conduct a study. The topic that I have chosen aims to find out more about clients (and their families), who have received Speech Therapy at a hospital or clinic. I want to find out how we can help them remember and understand what the Speech Therapist has told them so that they can follow the instructions at home.

You are invited to join a group discussion with other clients. You will have a chance to share your experiences of when you received Speech Therapy and tell us about your ability to understand, remember and use clinical information, provided to you by the Speech Therapist. Your suggestions on how we can improve your understanding and memory of clinical information will be welcomed.

There are no risks associated with this research project. The results of this study may help therapists and other researchers get a better understanding of what problems exist when it comes to your understanding and memory of clinical information and how we can improve on that.

The group discussion will take place at a time judged to be appropriate for most of the participants (e.g. at the hospital or clinic). A tape recorder will be used so that I can record exactly what you say. This tape will only be listened to by the research team. Your personal details and the fact that you personally made specific statements will be kept secret (confidential) at all times. However, I cannot *guarantee* confidentiality because some participants may share what was discussed outside of the group. This is why I ask you kindly to respect fellow participants' confidentiality at all times.

This whole process is not expected to take more than 1 hour 30 minutes and refreshments will be provided. We cannot pay you for taking part in the group discussions but we will give you money for travelling. A copy of my results will be made available to you when I am finished with my study, should you wish to read it.

You may pull out from participating in this study at any time, without giving a reason and without it having any negative effect on your (or your child's) future treatment.

I thank you for your time.

Yours faithfully,

Friderike Schmidt von Wühlisch

*Should you have any questions please contact me on 076 902 2803 or my supervisor Michelle Pascoe on 083 379 8746 / 021 406 6043.*

*If you have any questions about your rights and welfare as a research participant, please contact Prof Marc Blockman, Chairperson - Human Research Ethics Committee, 021 406 6496.*

---

**RETURN SLIP:**

I, \_\_\_\_\_ (*full name in print*) understand my rights as a research participant and I voluntarily agree to participate in this study. I understand what this study is about, my role in it and how and why it is being done. I have received a copy of this consent form.

---

**Signature of participant**

---

**Date**



Mnumzana/Nkosazana Obekekileyo

Umba: Uthatho nxaxhebo kuphando kwi-Dyunivesithi YaseKapa (Project).

Ndingumfundi owenza i-Master's kwi-Dyunivesithi YaseKapa, kwi candela kwi-Sebe lezeNgcaphephe kuNxebelelwano. Ukuze ndikwazi ukugqiba izifundo zam, kunya-nzelekile ukuba ndeze ingxelo malunga ngophanda. Uphando endilikhethileyo limalunga ngokwazi-ngcono ngezigulana (kunye nezalamane zebo), ezithe zafumana Unyango olubizwa nge-Speech Therapy esibhedlele. Sifuna ukwazi ukuba singabanceda njani ukuba bakhumbule, bayiqonde/bazi izinto kunye nemiqathango abayixelelweyo nguGqirha, ukwenzela ukuze bakwazi ukuzenza emakhaya.

Uyamenywa ukuba ubeyinxalenye yesigqeba sokusingatha ingxongxo, apho uzakuveza imbono okanye iimbono zakho kwindlela othe wafumana unyongo lwakho Lwesifo/Esichaphazela ukuthetha kunye neLwimi, kunye nendlela oyiqonda ngayo inkcukhacha yempilo othi uyifumane koo Gqirha bengxaki zokuthetha.

Uluvo Lwakho malunga nendlela ongakhulisa ngayo ulwazi lwakho kunye nokuhlala ukhumbula inkcukhacha ngempilo yakho, kwamkelekile.

Lengxoxo izakusingathwa kwindawo elungele wonke umntu othatha inxaxheba, (umzekelo: esibhedlele okanye eklinikhi). Lluke sikwazi ukugcina okuthethayo, kuyanzeleka ukuba kusetyenziswe isixhobo sokushicilela amazwi. Olushicilelo luzakumanyelwa ngabahlalutyi bophando. Inkcukhacha zakho neziphumo zoluphando luzakuhlala zisemfihlakalweni maxesha-onke. Kodwa asinakho ukuqinisekisa ukhuseleko lweziphumo, ngoba abanye abathathi nxaxheba baseno kuxelela umntu ongaphandle malunga neziphumo. Kungoko sinibongoza ukuba nihloniphe ukhuseleko lwenkcukhacha zabantu abathabathe inxaxheba koluphando, maxesha onke.

Lenqubo iyonke ayilendelekanga ukuba ingaqhubeka ixesha elingaphezulu kwe-yure enye ena-mashumi amathathu emizuzu, kwaye izidlwana zokuba zikhona. Asizukuhlawula nge nxaxheba yakho, kodwa singancedisa ngendleko zendlela xa kufanelekile. Luzakubakhona ushicilelo olubhaliweyo, hleze unqwenele ufunda iziphumo.

Usenokuqhawula esiphakathini soluphando nanini na, ngaphande kwesizathu.

Enkosi ngexesha kwanovelwano lwakho kule nxewe.

Ozithobileyo,  
Friderike Schmidt von Wühlisch

*Malunga nemibuzo, unganditsalela umnxeba kulenombolo 076 902 2803 okanye umphati wam uMichelle Pascoe kulenombolo 083 379 8746 / 021 406 6043.*

*Ba unemibuzo ngamalungelo wakho kunye nempatho eniyifumanayo wena mthathi nxaxheba sicela usiqhagamishele Prof Marc Blockman, Chairperson - Human Research Ethics Committee, 021 406 6496.*

---

**RETURN SLIP:**

Mna, \_\_\_\_\_ ndiyawazi amalungelo wam nje ngomthathi nxogxeba. Ndinga phumelela ukuba ngo mnye waba thathi nxaxheba. Ndiyayazi projethi (project) ingantoni ne ndima yam. Yenzeka njani nesizathu sokwenzima ndiyifumene incwadi ekufuneka ndiyi sayinile (sign).

---

**Siginitsha**

---

**Umhla**



Geagte Meneer/Mevrou,

Betrek: Deelname aan 'n navorsings projek by die Universiteit van Kaapstad.

Ek is a meester student van die afdeling vir spraak terapie en audiologie by die Universiteit van Kaapstad. Om my meester te slaag moet ek navorsing doen. Daarom het ek met 'n projek begin om meer oor pasiënte (en hul families) wat spraak terapie by 'n hospitaal ontvang het uit te vind. Ek wil ook uitvind hoe ons dit vir pasiënte makliker kan maak om dit wat die spraak terapeut vir hulle vertel het te verstaan en te onthou sodat hulle die wenke by die huis kan volg.

U is genooi om 'n groep met ander pasiënte/verplegers by te woon waar u die kaans sal he om oor u onderfindings met spraak terapie mee te deel. U sal ook oor u vermoë om die inligting van die spraak terapeut te verstaan en te onthou gevra word. U is welkom om 'n voorstel te doen oor wat ons kan doen om dit vir u makliker te maak om inligting wat die spraak terapeut gee te verstaan en te onthou.

U loop geen risiko as u besluit om aan die projek deel te neem. Die resultate van hierdie projek kan spraak terapeute en ander navorsers help om te verstaan wat die probleme is as dit kom by pasiënte se vermoë om inligting te onthou en te verstaan.

Die groep sal op 'n tyd en plek saam kom wat vir die meeste groep lede pas (bv. by die hospitaal of kliniek). 'n Kassetspeler sal gebruik word om alles wat in die groep bespreek word op te neem. Net die navorser sal na daardie kasset luister. U persoonlikhede en die feit dat u persoonlik iets gesê het sal heeltemaal geheim gehou word. Maar daar moet ook gesê word dat ek dit nie kan waarborg nie omdat dit moontlik is dat groep lede dit wat bespreek word met ander mense buite die groep sal deel. Dit is hoekom ek vir u mooi vra om ander groep lede se persoonlikhede altyd geheime te hou.

Die hele proses sal nie langer as een uur vat nie en iets om te eet en te drink sal aangebied word. Ons kan nie vir u betaal om aan die groep deel te neem nie maar ons sal vir u vervoer betaal. 'n Kopie van my finale raport sal vir u beskikbaar gemaak word as u dit graag wil lees.

U mag enige tyd uit die groep terugtree, sonder om 'n rede te gee.

Ek sê baie dankie vir u tyd en dat u hierdie saak bedink.

Hoogagtend,  
Friderike Schmidt von Wühlisch

As u enige vrae het, bel asseblief vir my op 076 902 2803 of vir my onderwyser Michelle Pascoe op 083 379 8746 / 021 406 6043.

As u enige vrae oor u regte en welsyn as 'n deelnemer in hierdie projek het, bel asseblief vir Prof Marc Blockman, Chairperson - Human Research Ethics Committee, 021 406 6496.

---

**RETURN SLIP:**

Ek, \_\_\_\_\_ (volle naam in drukskrif) verstaan my regte as 'n deelnemer van hierdie projek en ek gee vrye toestemming om aan die projek deel te neem. Ek verstaan or wat hierdie projek gaan, wat my rol is en ook hoe en hoekom die projek gedoen word. Ek het 'n kopie van hierdie toestemmings form gekry.

---

Handtekening

---

Datum

## Appendix F: Phase Two; Consent Form for the SLP taking part in research intervention



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**Faculty of Health Sciences**

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Occupational Therapy · Physiotherapy  
Old Main Building · Groote Schuur Hospital · Observatory · 7925  
Telephone: + 27 21 406 6401  
Fax: + 27 21 406 6323

Dear Sir/Madam,

Re: Participating in research project at the University of Cape Town

I am a Master's student in the Department of Communication Sciences and Disorders at the University of Cape Town. In order for me to complete my degree, it is required that I conduct a research report. The research topic that I have selected aims to (a) explore health literacy and information recall/memory of clients receiving Speech-Language Pathology treatment in a tertiary care hospital/rehabilitation clinic in Cape Town, and (b) to explore ways of maximising health literacy and client recall/memory of clinical information in this population, with special interest in the areas of swallowing (dysphagia) and voice disorders, laryngectomies as well as cleft lip and/or palate management.

You are hereby invited to participate in the intervention phase of this study. You would not need to do anything different from your routine intervention with clients, apart from using three proposed strategies to support client health literacy and recall/memory of clinical information. These strategies will be discussed and trialled with you at your convenience and should not detract from routine treatment or take up more than 5 minutes of your time per consultation. I need the strategies to be employed with one clients (or caregivers thereof) who present with any of the above-mentioned disorders. Clients who would be suitable participants for the intervention phase of this study would be discussed and identified by both you and me. After the clients and caregivers thereof have returned for a reassessment, you would need to fill out a questionnaire to provide feedback on the strategies that were utilised. Subsequently, a semi-structured interview will be held with you which will be guided by your answers to the questionnaire.

There are no risks associated with this research project. The results of this study may help therapists and other researchers get a better understanding of what barriers exist when it comes to clients' understanding and recall/memory of clinical information and how this can be maximised.

In order to record exactly what you say in the interview, a tape recorder will be used. This tape will only be listened to by the research team. Your details will be kept confidential at all times. This entire process is not expected to take more than 45 minutes. A copy of the final research report will be available to you, should you be interested to read it.

You may withdraw from participating in this study at any time, without having to give a reason for doing so.

Please be advised that once this study is completed, I will hold a talk about the outcomes of this study. All participants will be invited and there are CPD points to be had, should you decide to attend this talk.

I thank you for your time and your consideration of this matter.

Yours faithfully,

Friderike Schmidt von Wühlisch

*Should you have any questions, please do not hesitate to contact me on 076 902 2803 or my supervisor Michelle Pascoe on 083 379 8746 / 021 406 6043.*

*Should you have any queries about your rights and welfare as a research participant, please feel free to contact Prof Marc Blockman, Chairperson - Human Research Ethics Committee, 021 406 6496.*

---

**RETURN SLIP:**

**Biographical Details** *(for purpose of overview of participants' profiles)*

**Name:** .....

**Occupation & Place of practice:** .....

**Qualification:** .....

**Years of practice in public tertiary healthcare** .....

**Most experience in** ..... **(disorders)**

**Contact details:** .....

I, \_\_\_\_\_ *(full name in print)* understand my rights as a research participant and I voluntarily consent to participating in this study. I understand what this study is about, my role in it and how and why it is being done. I have received a copy of this consent form.

\_\_\_\_\_  
participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of

## Appendix G: Phase Two; English and Afrikaans Consent Forms for participants taking part in research intervention



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Telephone: + 27 21 406 6401  
Fax: + 27 21 406 6323

Dear Sir/Madam,

Re: Participating in research project at the University of Cape Town

I am a Master's student in the Department of Communication Sciences and Disorders at the University of Cape Town. In order for me to complete my degree, I must conduct a research report. The topic that I have chosen aims to find out more about clients (and their families), who have received Speech Therapy at a hospital/clinic. I want to find out how we can help them remember and understand what the Speech Therapist has told them so that they can follow the instructions at home.

You are hereby invited to participate in this study. The routine treatment or therapy that you (or your child) will receive will not be affected. When you come for a reassessment in a few weeks time, you will be asked to take part in a short interview. This is to get your feedback on some strategies that the Speech Therapist used.

A tape recorder will be used so that I can record exactly what you say. This tape will only be listened to by the research team. Your details and the fact that you personally made specific statements will be kept secret (confidential) at all times. I will not need more than 45 minutes of your time. Unfortunately I cannot pay you for taking part in this study. A copy of my results will be made available to you when I am finished with my study, should you wish to read it.

There are no risks associated with this research project. The results of this study may help therapists and other researchers get a better understanding of what problems exist when it comes to your understanding and memory of clinical information and how we can improve on that.

You may pull out from participating in this study at any time, without giving a reason and without it having any negative effect on your (or your child's) treatment.

I thank you for your time.

Yours faithfully,

Friderike Schmidt von Wühlisch

*Should you have any questions please contact me on 076 902 2803 or my supervisor Michelle Pascoe on 083 379 8746 / 021 406 6043.*

*If you have any questions about your rights and welfare as a research participant, please contact Prof Marc Blockman, Chairperson - Human Research Ethics Committee, 021 406 6496.*

---

**RETURN SLIP:**

I, \_\_\_\_\_ (*full name in print*) understand my rights as a research participant and I voluntarily consent to participating in this study. I understand what this study is about, my role in it and how and why it is being done. I have received a copy of this consent form.

---

Signature of participant

---

Date

University of Cape Town



Geagte Meneer/Mevrou,

Betrek: Deelname aan 'n navorsings projek by die Universiteit van Kaapstad.

Ek is a meester student van die afdeling vir spraak terapie en audiologie by die Universiteit van Kaapstad. Om my meester te slaag moet ek navorsing doen. Daarom het ek met 'n projek begin om meer oor pasiënte (en hul families) wat spraak terapie by 'n hospitaal ontvang het uit te vind. Ek wil ook uitvind hoe ons dit vir pasiënte/verplegers makliker kan maak om dit wat die spraak terapeut vir hulle vertel het te verstaan en te onthou sodat hulle die wenke by die huis kan volg.

U is genooi om aan hierdie projek deel te neem. U (of u kind se) gewone behandeling of terapie sal nie beïnvloed word nie. Wanneer u na 'n paar weke terug keer om te sien hoe u gevorder het sal u gevra word om 'n paar vrae gedurende 'n kort onderhoud te beantwoord. Dit sal fokus op wat u dink oor 'n paar strategieë wat die spraak terapeut gebruik het om dit vir u makliker te maak om informasie te verstaan en te onthou.

U loop geen risiko as u besluit om aan die projek deel te neem. Die resultate van hierdie projek kan spraak terapeute en ander navorsers help om te verstaan wat die probleme is as dit kom by pasiënte se vermoë om inligting te onthou en te verstaan. Verder sal dit ook inligting gee tot hoe spraak terapeute pasiënte/verplegers se vermoë om inligting te onthou en te verstaan kan ondersteun.

'n Kassetspeler sal gebruik word om alles wat u sê op te neem. Net die navorsers sal na daardie kasset luister. U persoonlikhede en die feit dat u persoonlik iets gesê het sal heeltemaal geheim gehou word. Ek sal nie meer as 45 minute van u tyd nodig hê nie. Ongelukkig kan ek nie vir u betaal as u besluit om aan my projek deel te neem. 'n Kopie van my finale rapport sal aan die einde van my projek vir u beskikbaar gemaak word as u dit graag wil lees.

U mag enige tyd besluit om nie meer aan die projek deel te neem nie, sonder om 'n rede te gee en sonder dat dit enige negatiewe effek op u of u kind se behandeling sal hê.

Ek sê baie dankie vir u tyd en dat u hierdie saak bedink.

Hoogagtend,

Friderike Schmidt von Wühlisch

*As u enige vrae het, bel asseblief vir my op 076 902 2803 of vir my onderwyser Michelle Pascoe op 083 379 8746 / 021 406 6043.*

*As u enige vrae oor u regte en welsyn as 'n deelnemer in hierdie projek het, bel asseblief vir Prof Marc Blockman, Chairperson - Human Research Ethics Committee, 021 406 6496.*

---

**RETURN SLIP:**

Ek, \_\_\_\_\_ (*volle naam in drukskrif*) verstaan my regte as n deelnemer van hierdie projek en ek gee vrye toestemming om aan die projek deel te neem. Ek verstaan or wat hierdie projek gaan, wat my rol is en ook hoe en hoekom die projek gedoen word. Ek het n kopie van hierdie toestemmings form gekry.

---

**Handtekening**

---

**Datum**

University of Cape Town

## Appendix H: Phase one; Consent Form for interpreter



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Telephone: + 27 21 406 6401  
Fax: + 27 21 406 6323

Dear Sir/Madam

Re: Offering interpreter services to a research project at the University of Cape Town.

I am a Master's student in the Department of Communication Sciences and Disorders at the University of Cape Town. In order for me to complete my degree, it is required that I conduct a research report. The research topic that I have selected aims to (a) explore health literacy and information recall/memory of clients receiving Speech-Language Pathology treatment in a South African public healthcare facility (b) to explore ways of maximising health literacy and client recall/memory of clinical information in this population.

As part of this research project, a focus group will be conducted which in this case is a group discussion between clients who have received some form of Speech Therapy in the past. The group will include participants who are isiXhosa speaking and in order for discussions to be possible in every participant's native language, your services are necessary. You will be required to translate isiXhosa into English and vice versa.

In order to record exactly what is discussed in the focus group, a tape recorder will be used. This tape will only be listened to by the research team. Your details will be kept confidential at all times. It is also essential that you keep other participants' personal details confidential at all times.

There has been an agreement between you and your supervisor, that you will not receive any financial compensation for your services. However, a small token of gratitude will be provided to you.

This entire process is not expected to take more than 1 hour 30 minutes. Refreshments will be provided.

I thank you for your time and your consideration of this matter.

Yours faithfully,  
Friderike Schmidt von Wühlisch

*Should you have any questions, please do not hesitate to contact me on 076 902 2803 or my supervisor Michelle Pascoe on 083 379 8746 / 021 406 6043.*

**RETURN SLIP:**

I, \_\_\_\_\_ (*full name in print*) understand my rights as an interpreter in this research project and I voluntarily consent to offering my services to this study. I understand what this study is about, my role in it and how and why it is being done. I have received a copy of this consent form.

\_\_\_\_\_  
Signature of interpreter

\_\_\_\_\_  
Date

University of Cape Town

## Appendix I: Tables 5. with background information on case studies

Table 5.1. Case Study One

Case number	Speech-Language Pathology service provided for...	Literacy Skills	Resides in...	Home Language	Employment
<i>Case # 1 (female aged 56)</i>	Post-operative counselling after total laryngectomy	Cannot read or write	Rural area	Afrikaans	Unemployed
Treating SLP	Years of experience in the field and in working in public health	Strategies that are usually employed		Home Language	Employed at
<i>Female</i>	27	<ul style="list-style-type: none"> <li>• Verbal instruction</li> <li>• Education</li> <li>• Demonstration</li> <li>• Repetition</li> <li>• Illustrations</li> <li>• Assist while independence is established</li> <li>• Information brochures and pamphlets</li> <li>• Provides work number and occasionally mobile phone number</li> </ul>		English	Tertiary Hospital

Table 5.2. Case Study Two

Case number	Speech-Language Pathology service provided for...	Literacy Skills	Resides in...	Home Language	Employment
<i>Case # 2 (caregiver aged 33)</i>	Provision of information, counselling and feeding recommendations for premature infant with cleft palate	No English literacy skills	Urban area	Somali	Unemployed
Treating SLP	Years of experience in the field and in working in public health	Strategies that are usually employed		Home Language	Employed at
<i>Female</i>	14	<ul style="list-style-type: none"> <li>• Verbal feedback</li> <li>• Counselling</li> <li>• Information brochures and pamphlets</li> <li>• Provides work and occasionally mobile phone number</li> </ul>		English	Tertiary Hospital

Table 5.3. Case Study Three

Case number	Speech-Language Pathology service provided for...	Literacy Skills	Resides in...	Home Language	Employment
<i>Case # 3 (male aged 41)</i>	Was educated about reasons for swallowing difficulties and received recommendations for feeding as well as exercises for dysarthria	Only finished school up to grade 4. Says he has difficulty reading complex text	Informal settlement	Afrikaans	Unemployed
Treating SLP	Years of experience in the field and in working in public health	Strategies that are usually employed		Home Language	Employed at
<i>Female</i>	2	<ul style="list-style-type: none"> <li>• Illustrations</li> <li>• Keeping aims at a minimum</li> <li>• Repetitions</li> <li>• Using teach-back method</li> <li>• Written instructions for caregivers</li> </ul>		English & Afrikaans	Community Clinic

Table 5.4. Case Study Four

<b>Case number</b>	<b>Speech-Language Pathology service provided for...</b>	<b>Literacy Skills</b>	<b>Resides in...</b>	<b>Home Language</b>	<b>Employment</b>
<b>Case # 4 (female aged 53)</b>	Counselling for the prevention of vocal abuse and misuse	Moderate literacy skills	Urban area	Afrikaans	Employed as a tea-lady
<b>Treating SLP</b>	<b>Years of experience in the field and in working in public health</b>	<b>Strategies that she usually uses</b>		<b>Home Language</b>	<b>Employed at</b>
<b>Female</b>	8	<ul style="list-style-type: none"> <li>• Written instructions</li> <li>• Teach-back method</li> <li>• Informing caregivers and significant others about the client's disorder and treatment</li> </ul>		English	Tertiary Hospital

University of Cape Town

## Appendix J: Phase One; Procedures and Semi-structured Interview Schedule for Focus Groups with SLPs

Participants were welcomed and thanked for deciding to be involved in the study. They were then reminded about the following:

- In order to record exactly what was discussed in the focus group, a tape recorder would be used. This tape would only be listened to by the research team.
- Their details would be kept confidential at all times. However, the researcher could not *guarantee* confidentiality as it was possible that some participants might share what was discussed outside of the group. This is why the researcher asked participants kindly to respect fellow participants' confidentiality at all times.
- This entire process was not expected to take more than 1 hour 30 minutes.
- Participants were allowed to withdraw from participating in this study at any time, without having to give a reason for doing so.
- A copy of the final research report would be available should they be interested to read it
- Participants were also advised that once this study was completed, a talk would be held by the researcher about the outcomes of this study. All participants would be invited and there were CPD points to be had, should they have decided to attend this talk.

Subsequently, consent forms were handed out to be signed and mobile phones had to be turned off. The role of the researcher was explained as mainly asking questions and listening. Participants were advised that they were free to speak to each other and that it was important that everyone was involved in discussions.

It was further explained where they as a focus group and participants would fit into the study. A background to the study was given. Important concepts were clarified and rationales for why the focus was on management of dysphagia, voice disorders (including laryngectomies) and cleft lip and/or palate management were given. Questions to start discussions followed.

All the while it was important to remember that this was a discussion and participants were free to speak about anything. Questions posed by the researcher were not supposed to be leading. At the end of the discussions, participants were thanked and before the group was dissolved, they were asked about contacts for possible participants for focus group B.

- 1) Are clients who have difficulties understanding your clinical information and the recommendations you give them an issue which you deal with often?
  - If yes, what do you think are the reasons for this?
  - If no, what do you think are the reasons for this?
  - Can you give me some examples of when you encountered such a situation?
- 2) Are clients who did not remember important information and recommendations (after a consult) an issue which you deal with often?
  - If yes, what do you think are the reasons for this?
  - If no, what do you think are the reasons for this?
  - Can you give me some examples of when you encountered such a situation?

- 3) Can you say something about the impact of clients' health literacy and their memory of recommendations (after a consult) on the success of treatment?
  - What do you think about the impact of these issues on your workload and healthcare costs?
  - Can you give me some examples?
- 4) Research has shown that health professionals often overestimate clients' degree of health literacy and recall of clinical information. Could you talk about the likelihood of SLPs assuming that their clients have understood their diagnosis and will remember recommendations (after a consult)?
  - Do you think it happens frequently?
  - What are the implications of this?
- 5) When it comes to assuring your client understands their diagnosis and remembers your recommendations, are there any strategies that you would/could use?
  - Can you give me some examples?
  - Considering your strategies, what would you do if a client cannot read and has inadequate English skills?
  - What are your thoughts on some of the information technology that is available? (Give some of my examples after they gave their suggestions and discuss them...)
- 6) If you had to pick three strategies, which would be your best three?
  - What would possible advantages be?
  - What would possible disadvantages/barriers be? How could these be overcome?
- 7) What is your view on the impact that these strategies could have on outcomes/success of therapy/interventions?
- 8) Could you expect clients to be more satisfied and assertive in managing their own health if these strategies would be used?
- 9) Let's conclude by each of you summarising your thoughts:
  - What is the biggest issue for you when it comes to (a) health literacy and (b) client memory in South Africa?
  - Please give your final comment on the idea about a possible system which would allow clients to review clinical information, ask questions and receive feedback after the actual consultation?

## **Appendix K: Phase One; Procedures and semi-structured Interview Schedule for Focus Groups with Past-clients thereof**

Participants were welcomed, introduced to each other and thanked for deciding to be involved in the study. They were then reminded about the following:

- In order to record exactly what was discussed in the focus group, a tape recorder would be used. This tape would only be listened to by the research team.
- Their details would be kept confidential at all times. However, the researcher could not *guarantee* confidentiality as it was possible that some participants might share what was discussed outside of the group. This is why the researcher asked participants kindly to respect fellow participants' confidentiality at all times.
- This entire process was not expected to take more than 1 hour.
- Participants were allowed to withdraw from participating in this study at any time, without having to give a reason for doing so.
- They were assured that there were no risks associated with their participation in this project and that their withdrawal would not affect the future provision of treatment or therapy that they were entitled to at any of the clinics or hospitals.
- An interpreter was made available to translate English into isiXhosa and vice versa.
- Participants were given a chance to voice their choice of language for discussion. The researcher offered to phrase the questions in English and then Afrikaans to ensure that all participants understood and the interpreter could then translate what was said into isiXhosa.
- A copy of the final research report would be made available should they be interested to read it.

Subsequently, consent forms were handed out to be signed and mobile phones had to be turned off. The topic of this discussion was introduced briefly as (a) wanting to hear about past-clients'/their caregivers' views on their ability to remember and understand what the speech therapist told them and (b) further discussing what could be done to aid in clients understanding and remembering what the speech therapist said. It was further explained where they as a focus group and participants would fit into the study.

The researcher's role in this discussion was explained as mainly asking questions and listening. Participants were advised that they were free to speak to each other and that it was important that everyone was involved in discussions.

Questions to start discussions followed. All the while it was important to remember that this was a discussion and participants were free to speak about anything. Furthermore, it was also important to note that participants might have been naive about the topic of discussion and therefore a minimum degree of guidance was potentially necessary to generate data which was question specific. At the same time, questions posed by the researcher were not supposed to be leading. At the end of the discussions, participants were thanked and the group was dissolved. Time was allowed for individual discussions among participants as it seemed that individuals had urgent questions and felt they needed to share experiences with each other.

- 1) When you saw the speech therapist, how much time did he/she spend with you?
  - Did you think it was enough time to understand and remember everything that was said?
- 2) Can you tell me about what it is that makes it difficult for you to understand and remember what the speech therapist told you?
- 3) What is it that makes it easy for you to understand and remember what the speech therapist told you?
- 4) Tell me a little bit about when you leave the speech therapist and you go home. Do you always remember and understand what he/she has said to you?
  - Do you always follow exactly what he/she tells you to do?
  - If not, what makes it difficult for you to do so?
  - How does that make you feel?
  - What do you do instead?
- 5) Tell me how you feel about asking the speech therapist questions?
  - How do you feel about telling the speech therapist that you could not understand or remember what he/she said?
  - Do you feel you can do that easily?
  - When is that difficult for you?
- 6) What method did the speech therapist use to give you health information or recommendations? (give examples if they do not understand)
  - Did it make it easier or more difficult for you to *understand* the information that he/she gave you?
  - Did it make it easier or more difficult for you to *remember* the information that he/she gave you?
- 7) Let me give you some examples of methods that speech therapists often use to give information and you tell me what you like or dislike about them.
  - Written pamphlets
  - Phone calls (receiving and or making a phone call to a speech therapist)
  - Pictures
  - Practicing in the session
  - Bringing a family member
  - Videos
- 8) Now let me give you some examples of a few other methods to exchange information and you tell me what you like or dislike about them.
- 9) How do you think we can improve your understanding and memory of the information that the speech therapist gives you?

## Appendix L: Phase Three; Interview Schedule for the participant (client) after research intervention

### Demographic Information (information gathered in phase 2)

Name: \_\_\_\_\_ Age: \_\_\_\_\_

Home language(s): \_\_\_\_\_ Ethnicity/Race: \_\_\_\_\_

Home address: \_\_\_\_\_ Contact nr: \_\_\_\_\_

Occupation: \_\_\_\_\_

Last appointment with the Speech Therapist \_\_\_\_\_

What information materials did the Speech Therapist give you to take home? \_\_\_\_\_

### Section A: Audio-recording

1) Did you feel the need to listen to the CD/tape that we gave you?

**If answer is YES:** How many times did you listen to it?

**If answer is NO:** Can you explain what the reasons were?

2) After you left the consultation. Was there anything that you did not *understand* or could not *remember*?

**If answer is YES:** What kind of information was that?

3) So do you think that the CD/tape helped you to *understand* and *follow* all the important recommendations that the speech therapist gave you?

**If answer is YES:** How so?

**If answer is No:** Can you explain what the reasons were?

4) Did this CD/tape help you in *managing* your own/your child's health problem?

**If answer is YES:** How so?

**If answer is NO:** Can you explain what the reasons were?

5) Did someone else listen to the CD/tape?

**If answer is YES:** What did they think of it?

6) Did this CD/tape help you to explain and discuss all the information and recommendations with your family?

**If answer is YES:** How so?

**If answer is No:** Can you explain what the reasons were?

7) Do you think that we should give every client a CD/tape to take home with all the information that is given by the speech therapist?

**If answer is YES:** Can you explain what the reasons were?

**If answer is NO:** Can you explain what the reasons were?

### **Section B: SMS (please call me) and telephonic follow-up**

8) When you had a problem or difficulties with the recommendations, did you find it necessary to send a “please call me” SMS to your speech therapist?

**If answer is YES:** Please explain what happened.

**If answer is NO:** Can you tell me what the reasons were?

9) Did you find it convenient to send a “please call me” SMS to your speech therapist, to let her know that she must phone you?

**If answer is YES:** Please explain...

**If answer is NO:** Can you explain what the reasons were?

### **Section C: Summary**

10) What was your overall experience of the Speech Therapy treatment and management of your/your child’s health problem?

**Any additional comments?**

*At the end, participants were thanked for assisting the researcher with her project.*

## Appendix M: Phase Three; Questionnaire for the SLP after research intervention

The contents of this form are absolutely confidential. Information identifying *you* as a respondent will not be disclosed under any circumstances.

### Demographic Information:

Name: \_\_\_\_\_  
Years of experience in the field: \_\_\_\_\_

Home language(s): \_\_\_\_\_

Strategies you already use to improve health literacy and client recall/memory of your recommendations:

NONE

I DO (please specify) \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Please complete with regards to the treatment of (*specify client initials here*):

\_\_\_\_\_

Where applicable, please circle one of the options on the rating scale below  
SA=strongly agree; A=agree; U=unsure; D=disagree; SD=strongly disagree

Other questions will require you to tick, circle or write your responses

The questions below focus on your experience from the first to the latest consultation with the above client

*Please read all the questions with care and take time to give your true opinion  
Please do not hesitate to ask questions for clarification*

In this questionnaire I refer to 'three strategies' or 'the combined strategies' which are (a) an audio-recording, (b) SMS (please call me) and (c) telephonic follow-up.

Continued...

1) I felt that the combination of these three strategies for **improving health literacy and client recall of clinical information in the above client** were... (*please circle which of the following applies*)

- *Impractical/practical*
- *A waste of time/time well spent*
- *unnecessary/necessary*
- *culturally appropriate/inappropriate*
- *user-friendly/not user friendly*
- *ineffectual/effective* in assuring continued contact and service delivery post-consultation
- *suitable/unsuitable* for information review by other health professionals
- *suitable/unsuitable* for information review by other family members
- *effective/ineffectual* in inducing compliance or behavioural change in the client
- generally *ineffectual/effective* in improving health literacy and client recall of clinical information, thus *decreasing/increasing* the efficacy of the treatment that I provided.

2) I felt that using the combined strategies for improving health literacy and client recall of clinical information made **a difference in the success of the client's treatment.**

SA            A            U            D            SD

3) I felt that the client was **more confident in managing their own (or their child's health)**, when they had the chance to;

a) review, understand and process audio-recorded clinical information at home and

b) be in regular contact with me for problem solving and discussion post-consultation.

SA            A            U            D            SD

Continued...

4) I felt that once the client had left the consultation, the information that they were taking with them was **(please tick)**

(a)  **clear, accurate and complete**  
*and / or*

(b)  **ready for review to improve understanding and recall of clinical information**  
at any stage **post-consultation.**

5) I do ***not*** feel that the combination of the three strategies is appropriate to use in the ...  
**(please tick)**

Management of dysphagia

Treatment of voice disorders

Management of people with laryngectomies

Management of cleft lip and/or palate

6) My reasons are... *(please give a rationale for your answer to question five)*

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7) What other factors (e.g. personal, contextual, procedural) do you think affected the effectiveness of the three strategies in this case?

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8) As an improvement/alteration of the combination of these three strategies I would suggest:

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Continued...

9) As a complete alternative to the combination of these three strategies, I would suggest the following: \_\_\_\_\_

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10) Overall, I had a **negative** experience when using the strategies for improving health literacy and client recall of clinical information.

**SA                      A                      U                      D                      SD**

11) Following the completion of this study, do you feel that you would like to routinely use the combination or part of these three strategies in future sessions?

**YES** (please provide reasons for your answer): \_\_\_\_\_

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**NO** (please provide reasons for your answer): \_\_\_\_\_

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*GENERAL QUESTION*

12) When it comes to **improving health literacy and recall of clinical information LONG after the initial consultation**, I find the combination of the three strategies for clients that

- reside in rural/impooverished areas →  useful  not useful
- have low health or general literacy skills →  useful  not useful
- do not have sufficient English language skills →  useful  not useful
- Other suggestions?

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**Any additional comments?**

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*Thank you very much for taking time to fill out this questionnaire. It will now be followed by a short interview to probe more deeply into some of the answers that you provided.*

## Appendix N: Transcript of Interviews conducted in Case Study # One.

**R** = Researcher

**P1** = Client

... means there was a pause or an omission of irrelevant chat/conversation.

**R:** My eerste vraag is, het mevrou na die tape geluister wat ek vir mevrou gegee het?

**P1:** Ja ek het geluister.

**R:** En hoe veel keer het mevrou daarna geluister?

**P1:** So elke dag as ek lê, dan sit ek hom aan, dan luister ek.

**R:** Ok, so elke dag as mevrou gaan lê het in die aand, het mevrou daarna geluister?

**P1:** Ja in die middag ook...

**R:** Die middag ook toe mevrou by die huis was?

**P1:** Hm.

**R:** Ok, en was daar informasie op die klein tape wat mevrou nie verstaan het of vergeet het nadat mevrou van hier af gegaan het? Was daar enige informasie wat mevrou...toe mevrou na die tape geluister het gedink het; ooh dit het ek vergeet en ooh ja nou verstaan ek eers. Was daar enige so 'n informasie daarop?

**P1:** Hoe meen mevrou?

**R:** Ok so mevrou het mos hier gekom ne? En [the speech therapist] het mos soo baie goed vertel en verduidelik en so...en toe mevrou by die huis gekom het, kon mevrou goed onthou al die goed wat [the speech therapist] gesê het sonder dat mevrou nou na daardie ding geluister het?

**P1:** Ja, ek het bietjie vergeet...

**R:** Bietjie vergeet het mevrou is dit? Ok, wat is dit wat mevrou...kan mevrou vir my 'n voorbeeld gee wat mevrou vergeet het?

**P1:** Partykeer, dan vergeet ek hoe moet ek daardie borseltjie...om hom in te druk, [not audible] ingedruk want partykeer dan kry ek seer, dan los ek...

**R:** So partykeer was dit seer vir mevrou en dan het mevrou dit maar gelos.

**P1:** Ja, en daar is niemand wat vir my kan help nie...

**R:** Ja, ok en so watter informasie was daar wat mevrou vergeet het toe mevrou van hier af gegaan het? Watter informasie was dit wat mevrou vergeet het...so mevrou het gesê, hoe 'n mens dit in sit en

was daar nog iets anders wat mevrou nie verstaan het nie of mevrou vergeet het, toe mevrou daar uitgeloop het die eerste keer?

**P1:** Hierso?

**R:** Ja.

**P1:** Nee.

**R:** Ok.

**P1:** Ek kon alles onthou.

**R:** Ok, so mevrou kon dit onthou?

**P1:** Ja.

**R:** En toe mevrou by die huis gekom het?

**P1:** Toe het ek die tapie aangesit...luister ek altyd.

**R:** Ja, en was dit omdat mevrou dit net alles wou verfris wat [the speech therapist] vir mevrou vertel het? Het mevrou na die ding geluister net om dit weer te hoor en weer te verstaan en...

**P1:** Uh hu.

**R:** So dink mevrou dat daardie klein tapie vir mevrou gehelp het om informasie weer te verstaan en te onthou?

**P1:** Ja, baie gehelp...

**R:** Is dit so dit het baie gehelp en wanneer het dit die meeste gehelp? Was dit toe mevrou by die huis gekom het en nou alleen was of het dit vir mevrou reg deur die weke gehelp?

**P1:** Deur die week as ek so alleenig is, dan sit so, dan sit ek hom aan.

**R:** So was dit ook net om vir mevrou, dat mevrou [the speech therapist's] se stem gehoor het en...

**P1:** Ja...

**R:** Is dit? Dis baie interessant. Ok, so dit het gehelp dat dit [the speech therapist] se stem was maar het dit ook gehelp dat jy altyd weer die informasie geluister het om dan beter te verstaan?

**P1:** Ja... Ek raak moeg...

**R:** Mevrou raak moeg as mevrou baie praat? Dit vat seker ook baie tyd om daaraan gewoon te raak...

**P1:** Want ek het nie baie by die huis gepraat nie want daar is niemand wat ek mee kan praat nie...

**R:** Ok en mevrou het iets gesê oor mevrou se man...

**P1:** Hy was baie ongeduldig...

**R:** Hy was baie ongeduldig is dit...hoe so?

**P1:** Nee ek het baie snaaks geraak...

**R:** Hoe bedoel mevrou?

**P1:** Baie deurmekaar geraak by die huis...

**R:** Is dit...en hoekom was dit?

**P1:** [became emotional]

**R:** Dit is ok, mevrou kan maar alles vir my vertel. Want ek is mos nou hier en nou kan mevrou mooi met my praat en vir my alles vertel...was dit vir mevrou baie moeilik om so huis toe te gaan en niemand daar te hê wat mooi verstaan en so?

**P1:** Hm

**R:** Hm...ok en as mevrou sê mevrou het snaaks geraak, hoe bedoel mevrou?

**P1:** As ek so dink hoe ek was...ek was nie so nie.

**R:** Hm...mevrou was nie hoe nie? Hoe bedoel mevrou?

**P1:** Ek was nie die mens wat ek nou is nie.

**R:** Is dit...nou hoe is mevrou nou?

**P1:** Ek het gewerk, ek was gesond...ek was altyd gelukkig.

**R:** Mevrou was altyd gelukkig...

**P1:** Maar nou...

**R:** Ok, maar nou wat...wat is dit nou wat vir mevrou anders maak?

**P1:** Ek kan nie werk nie en my man is siek...

**R:** Mevrou se man is?

**P1:** Siekerig...hy werk nie elke dag nie...en nou werk ek ook nie...

**R:** So mevrou werk nou ook nie so mevrou het nou ook baie goed waaroor mevrou worry?

**P1:** Hm.

**R:** Hm ok maar ek dink nie daar sou...ek meen ek weet mevrou is nou al 52 en mevrou word nou ook oud maar daar kan mos miskien ook goed wees wat mevrou kan doen wat nou nie so baie met huiswerk en so is...goed wat nou nie so baie van mevrou se krag moet vat nie...mevrou kan mos miskien naaldwerk doen of sulke dinge of nie rerig nie? Is daar niks wat mevrou nou voel mevrou wil doen as dit by werk kom?

**P1:** Ek sal maar weer kyk om huiswerk...

**R:** Ja want dit sal miskien vir mevrou ook help as mevrou met iets besig is...dan sal mevrou nie so baie tyd hê om hartseer te wees en...verstaan mevrou? As mevrou iets kry waarmee mevrou kan besig wees en ook praat met mense want as mevrou so by die huis sit en niemand het om te praat nie...dit is nie reg vir enige mens nie...ek meen dit sal vir enige mens hartseer maak en nie reg laat voel nie. So ek dink as mevrou nou by die huis kom weer nadat ons hierdie weer uitsorteer het en so dan moet mevrou maar probeer om weer in te kom by die werk en besig te raak en...want hierdie is

nie so 'n erge ding nie. Mevrou kan mooi v&euml;r aan gaan met mevrou se lewe, mevrou se stem sal na 'n tyd weer mooi klink. Dit sal nie klink soos dit voorheen geklink het maar mevrou sal jou eie stem kry... maar dit sal net kom as mevrou dit baie meer gebruik...

**P1:** As ek net weer my werk kan terug kry...die man wat ek by gewerk het... hy is nou bang om vir my terug te vat.

**R:** Hoekom is hy bang?

**P1:** Hy s&euml; hy is bang ek het snaaks geraak by die werk en ek is alleen by sy huis.

**R:** Oh so hy is bang iets gebeur met mevrou en mevrou is alleen by die huis...

**P1:** Ja by sy werk...nou ek vra hy moet my uitbetaal vir die vier jaar...

**R:** Oh vier jaar wat mevrou daar gewerk het...ok dan moet mevrou dit maar doen...maar mevrou moet maar praat dan ook. Dit is nou die probleem want mevrou kan mos nie skryf nie, mevrou het mevrou se stem nodig om te s&euml; wat mevrou wil h&euml; so ek dink later as mevrou by [the speech therapist] is, moet mevrou maar net vir haar verduidelik; dit is wat ek moet doen as ek by die huis kom so ek moet kan praat ...want ek dink sy wou hierdie ding uithaal sodat mevrou nie kan praat nie...so mevrou moet maar later met haar praat...en uitvind as sy dit uithaal, hoe sal mevrou praat... of hulle dit kan inhou dat mevrou kan praat want hierdie klein plastic ding wat mos daar in sit, hy moet daar in wees as mevrou wil praat. As hy uitgehaal word sal mevrou nie kan praat nie...so mevrou moet maar vra daar en praat met haar en vra haar vrae dit is waarvoor sy daar is...mevrou moet nie bang wees nie... vra haar alles en mevrou kan mos nou so mooi praat...toe ons mos vir mevrou die eerste keer gesien het was dit mos moeilik vir mevrou om te praat en ek weet mevrou het baie goed wat mevrou wil s&euml; maar dit is moeilik vir mevrou om dit alles uit te kry of hoe?

**P1:** Dit is 'n bietjie moeilik rerig...

**R:** Hm wat maak dit moeilik?

**P1:** Ek raak net kortasem as ek so baie praat.

**R:** Ja maar ek dink as mevrou dit meer gebruik...

**P1:** Dan sal ek nie so kortasem ja...

**R:** Dan sal dit beter word ja...mevrou moet oefen, oefen, oefen en dit is hoekom dit seker ook baie belangrik is dat mevrou iewers weer kan besig word...

**P1:** Ja as ek werk is ek gelukkig... nou moet ek net so sit by die huis...

**R:** Ja en mevrou kan mos nie eers 'n boek lees of so nie...

**P1:** Hu uh.

**R:** Het mevrou nooit skool toe gegaan nie?

**P1:** Nee, van kleins af moet ek gewerk het...

**R:** Is dit...het mevrou se man na die klein tapie geluister?

**P1:** Ja in die aande...

**R:** Hoe veel keer het hy daarna geluister?

**P1:** So in die aande...

**R:** In die aande saam met mevrou?

**P1:** Ja.

**R:** Ok, en wat het hy gesê?

**P1:** Hy verstaan nie mooi nie wat aan gaan want hy vra vir my wat is die gat?

**R:** Ok maar kon mevrou toe nie die prentjies vat en...

**P1:** Ja, ja...

**R:** Het mevrou, so mevrou het die prentjies gevat en gewys...

**P1:** Vir hom gewys...hy verstaan niks...hy sê ek moet die dokter sê, die dokter moet die gat toe maak...

**R:** So hy verstaan nie dat die gaatjie daar moet bly?

**P1:** Ek sê vir hom, dit is my gesondheit die, my asem kom hier uit, hy vra kom my asem nie uit my mond nie? Hy wil niks verstaan nie. Hy sê ek moet vir dokter sê, hy moet die gat toe maak.

**R:** Ok so die tape en al die informasie wat daarop was...

**P1:** Hy kan nie verstaan nie...

**R:** Hy kan nie verstaan nie...dit is seker ook omdat hy nie hier is nie waar die goed gewys was. Hy het mos nou net iets gehad waar hy kan luister en die prentjies...

**P1:** Ja.

**R:** ... hy het nie 'n dokter gehaad wat vir hom kan verduidelik; kyk dit is hoe dit nou werk en dit is hoe dit sal altyd...Maar ek verstaan nie so mooi...want op daardie tapie was mos al die informasie wat [the speech therapist] gegee het van die begin tot die einde en...

**P1:** Ja. As hy my so kyk dan sê hy vir my; jy sê vir die dokter hy moet die gat toe maak, hy kan nie verstaan nie...

**R:** Hy kan nie verstaan nie...so dit maak nie saak hoe lank hy daarna luister...

**P1:** Hy kan dit net nie verstaan nie...

**R:** Dink mevrou miskien hy kon dit verstaan maar hy wou nie verstaan nie...?

**P1:** Ek weet nie, as hy my nou so sit en kyk dan sê hy; jy sê vir die dokter hy moet die gat toe maak. Ek skud net my kop. Ek sê vir hom my gesondheit my asem kom hier deur. Dan vra hy vir my; maar jou asem kom by jou mond. Hy sê; jy eet dan met jou mond...

**R:** Ok, so het mevrou gegaan en die prentjies gewys en gesê; so is dit normal en so is dit hoe ek nou sal wees, want hulle het nou hierdie hier uitgehaal en nou vir my so gemaak...

**P1:** Hm.

**R:** ...saam met die tapie ook en alles?

**P1:** Hm, hy wil niks verstaan nie...hy sê hy wil hê ek moet lyk soos ek gelyk het...dis sy wil...

**R:** Ek dink hy het verstaan oor wat dit gaan miskien maar dit is miskien ook vir hom...hy wil nie graag daarmee vrede maak nie...

**P1:** Hy is nou die een wat net deurmekaar is, hy sê hy kan nie vat dat ek so lyk nie...hy kan dit nie glo nie...

**R:** Al het hy na die tapie geluister en die prentjies gekyk en so, hy wil dit nie glo nie...

**P1:** Ja, hy wil dit nie glo nie...en hy weet ek was nooit so gewees nie. Ek sê vir hom; Pieter, dit is die Here se wonderwerk, sê dankie vir die Vader dat ek lewe...hy kan dit nie verstaan nie, hy kan dit nie vergeet nie, hy kan dit nie glo nie.

**R:** Wat het hy oor daardie tapie gedink? Het hy gedink dit was 'n goeie idee dat mevrou dit gehaad het? Het hy gesê dit is 'n goeie ding of wat het hy daarvoor gesê oor die tapie en die prentjies? Het hy enige iets daarvoor gesê?

**P1:** Hy het altyd net geluister maar hy wou nie eintlik met my praat baie met my nie. Al wat hy sê is hy kan dit nie verstaan nie, hy kan dit nie glo nie...dat ek so lyk.

**R:** So hy het daarna geluister maar hy wou nie met mevrou daarvoor praat nie?

**P1:** Ja.

**R:** Ok, het mevrou probeer om vir hom te verduidelik?

**P1:** Baie, baie, baie...

**R:** En hoe het hy gereageer?

**P1:** Sy antwoord is net hy kan dit nie verstaan nie...hy kan dit nie glo nie, hy kan nie vergeet nie.

**R:** Ok sê nou maar as mevrou die tape nie gehaad het nie, sou dit vir mevrou meiliker gewees het om te verduidelik as mevrou dit nie gahaad het nie?

**P1:** Ek het hom verduidelik, baie verduidelik. Dan sê ek vir hom; Pieter [not audible] maar hy verstaan nie, hy sê net hy [not audible] daardie is al wat hy sê, hy kan dit nie glo nie, hy kan dit nie vergeet nie...hy wil dit net nie hanteer nie.

**R:** Maar het daardie tapie en die prentjies vir mevrou gehelp om vir hom te verduidelik?

**P1:** Dit het baie gehelp ja maar dit gaan nie in sy kop in nie...

**R:** Ok, op daardie tapie was mos baie informasie oor hoe mevrou dit moet skoon hou en wanneer mevrou daardie tjoepie moet in sit en so...het daardie tapie vir mevrou gehelp om dit alleen te doen al daardie goed?

**P1:** Ja maar partykeer dan kry ek seer, dan los ek, want hy wil my nie help nie want hy kry ook seer, hy...

**R:** Hy kan dit nie sien nie...

**P1:** Ja baie keer dan kry ek seer...

**R:** Het mevrou n' speltjie by die huis?

**P1:** Ja.

**R:** So ook met die speltjie is dit seer?

**P1:** Ja dis seer...

**R:** Maar toe mevrou by die huis gekom het kon mevrou onthou hoe om die in te sit of moes mevrou eers na die tapie weer luister om uit te vind hoe en waar dit moet in gaan en so...

**P1:** Ek is mos die saterdag oggend 5 o'clock weg in die Kaap. Toe kom ek saterdag nag 1 o'clock by die huis toe gaan sit ek die tjoepie in toe ek by die huis kom, toe vergeet ek nie...

**R:** En mevrou kon onthou van hier hoe en waar hy moet in gaan?

**P1:** Ja ek het.

**R:** Ok so mevrou moes nie na die tapie eers luister om weer te onthou nie?

**P1:** Nee.

**R:** Watter ander goed was daar op die tapie wat vir mevrou gehelp het om hierdie skoon te hou en...was daar enige ander informasie wat mevrou vergeet het en toe eers weer onthou het toe mevrou na die tapie luister?

**P1:** Die borseltjie vergeet ek om te draai, toe moet ek die tapie aan sit. Dan luister ek van die borseltjie waar moet ek hom indruk.

**R:** So dit kon mevrou eers weer onthou toe mevrou daarna geluister het?

**P1:** Ja.

**R:** En is daar enige iets anders wat daarop was wat vir mevrou gehelp het om die te manage...om dit skoon te hou en...

**P1:** Dan het ek nou die tapie angesit, dan weet ek nou van die lang rubber, maar ek het hom mos nie gebruik nie.

**R:** Wanneer moes mevrou hom weer gebruik? Kan mevrou onthou?

**P1:** Wanneer daardie...

**R:** Oh wanneer die klein ding uitval...

**P1:** Wanneer dit uitval ja...

**R:** Ok en kon mevrou dit onthou van die tapie of het mevrou dit al van hier onthou? Moes mevrou eers na die tapie luister om dit te onthou?

**P1:** Ja, maar daardie rubbertjie...het ek geluister by die tapie...van die rubberjie...

**R:** Wanneer mevrou hom moet gebruik...

**P1:** Ja omdat hy gaan uitval by die ding...

**R:** So mevrou het hom nie begruik nie want hy het mos nie uitgeval nie...

**P1:** Ja maar die klein rubbertjie...moet as daardie ding uitgeval het...dan moet ek mos daardie rubbertjie gebruik...

**R:** Dink mevrou...hierdie wat ons nou gedoen het met die tapie en die prentjies...dink mevrou dit is 'n goeie idee om dit vir ander pasiënte ook te gee?

**P1:** Dit is 'n baie goeie idee, ja baie goed...

**R:** Hoekom dink mevrou so?

**P1:** Want dit is wonderlik, daardie tapie help 'n mens baie...

**R:** Ek wou ook vir mevrou vra, watter ander redes is daar hoekom dit 'n goeie idee is dat ons dit vir ander pasiënte ook gee...mevrou het mos gesê dit is baie wonderlik maar watter ander redes is daar dat ons dit vir pasiënte kan gee?

**P1:** Hoe bedoel mevrou nou?

**R:** Is daar enige ander rede hoekom ons 'n tapie en prentjies vir ander pasiënte moet gee? Is dit miskien omdat mens na 'n stem kan luister of...hoekom is dit 'n goeie idee om dit vir ander pasiënte ook te gee?

**P1:** Omdat dit vir my gewees het...as ek iets vergeet dan sit ek die tapie aan, dan onthou ek...dan onthou ek alles ... want daar is baie kere wat ek vergeet...dan sit ek die tapie aan om te luister, en om te onthou...

**R:** So dit is om te onthou en is daar 'n ander rede? Mevrou het mos in die begin gesê dit is baie goed as 'n mens alleen is en 'n mens kan na 'n stem luister...is dit ook een rede?

**P1:** Ja.

**R:** En is daar nog iets anders?

**P1:** Nee...

**R:** Was daar 'n tyd waar mevrou 'n probleem gehaad het waar mevrou graag met [the speech therapist] wou gepraat het?

**P1:** Ek het vir Sharon gevra of sy my George hospital gaan vat, toe sê sy sy het nie geld vir petrol nie. Ons het vir haar 70R gegee maar sy sê sy het nie geld nie.

**R:** En het mevrou ooit na haar toe gegaan en gesê; kan ja asseblief vir [the speech therapist] bel want ek het n probleem...

**P1:** Ja en toe sê sy vir my sy sal vir [the speech therapist] bel en toe sê sy sy sal vir my kom sê by die huis maar sy het nooit kom sê nie...

**R:** Was daar enige tyd waar mevrou graag met [the speech therapist] wou gepraat het?

**P1:** Nee, Sharon het vir my gesê [the speech therapist] het gebel toe sê ek vir haar sy moet terug bel om te sê dit gaan goed met my...

**R:** So mevrou het toe net gesê dit gaan goed met mevrou...

**P1:** Ja.

**R:** So mevrou het nooit dit nodig gehaad om vir [the speech therapist] hierso te bel oor n probleem of so?

**P1:** Nee.

**R:** Ok, ons is nou by die laaste vraag. Wat is u hele...toe mevrou mos nou hier gekom het...ons het mos lank daar gesit en gepraat en ons het die tapie gegee en die prentjies. Hoe is mevrou se ontferming van hierdie hele terapie en wat ons vir mevrou gedoen het...is dit n goeie ondervinding of is daar dinge wat mevrou graag wil hê ons moet beter maak?...Ek weet nou mevrou kon mos nie met [the speech therapist] praat nie oor die phone so sou mevrou dit graag meer gedoen het...of was dit nie nodig nie? Sou mevrou graag meer met haar geophone het...as mevrou probleme het of net so om te praat?

**P1:** Nee ek het nie probleme gehaad nie...

**R:** Ok so dit was nie nodig vir mevrou nie...?

**P1:** Dit was nie nodig nie...

**R:** Ok, is daar enige iets anders wat mevrou graag wou hê wat ons kon beter gedoen het...?

**P1:** Nee, ek wil net vir [the speech therapist] vra of sy my nie kan help dat ek n toelaging kan kry nie. Dit wil ek met haar praat...dit is maar net vir n sekere tydjie dat ek net kan aan die lewe bly...

**R:** Ok, en is daar miskien enige iets wat ons kon beter gedoen het met u man dat u man miskien beter kan verstaan of so?

**P1:** Ja...

**R:** Wat sou mevrou voorstel wat ons daar kon gedoen het?

**P1:** Dat julle vir hom n mooi brief gee, dat hy kan lees...

**R:** n Brief skryf wat net vir hom is...

**P1:** Ja...dat hy kan verstaan...

**R:** Ok so n briefie of n phonecall?

**P1:** ń Brief...

**R:** Ok dat hy dit altyd weer kan lees...

**P1:** Ja.

**R:** Nie net soos ń phonecall wat hy dan weer sal vergeet nie...

**P1:** Ja, dat hy dit kan lees...

**R:** Ok, is daar enige iets anders?

**P1:** Nou weet ek nie meer [laughs]...

University of Cape Town

**R** = **Researcher**

**T1** = **Therapist**

... means there was a pause or an omission of irrelevant chat/conversation.

**R:** In the first question you said that you felt that the combination of these strategies was impractical and then you said because it was an added burden, you had to educate around this issue as well, what do you mean by that, you had to educate around this issue...which issue is that?

**T1:** Ok it's already, it was difficult enough giving her [the client] a lot of information about her stoma and her tracheostomy tubes and how to speak so she had a fortune of information already. She obviously has no experience with tape-recorders or mobile phones and so I now had to teach her about the tape recorder and the mobile phone and where to go and what to do and all of the above. So I just felt it was just more information about how to use the strategies as well...

**R:** Ok, that makes sense. And then you said time well spent. Do you think that was because...it was an additional...ja you said it was however time well spent.

**T1:** Ok, I think that if we had used it I mean...it's impractical because it's a lot ... we did tell her what to do and so it's hard to always judge the insight or sort of intellect so that if she did cotton on, then it was time worth well spent. Ahm... but it does place an added burden so... but it's worth trying I think in people who are illiterate you want to try as many avenues if you can...

**R:** Ok...

**T1:** ... I mean it seems contradictory too but ahm...

**R:** ...No but it makes sense...

**T1:** ...you know, we did it so it was time well worth spent, whether I would want to do it in future that's the issue.

**R:** Ok...then you said it was unnecessary and inappropriate...ahm why do you think so?

**T1:** Again as I've said, I kind of got to know her and her lack of experience in these. I also know that she was mostly alone at home and she just had a husband who didn't really appear very supportive and she wouldn't be the one that would go to the white lady, you know that's not always around so she was fairly isolated so in her case probably... not that indicated.

**R:** Ok, so it was unnecessary and inappropriate because of the factors that played a role with this specific client ...

**T1:** This specific client...

**R:** ... she was alone, and she didn't have support and she didn't have [full] access really to a mobile phone or a phone and ...

**T1:** Yes... and she wasn't used to using a mobile phone in any case, she doesn't have one.

**R:** ... Ja and you said user-friendly but then not for her... do you mean...

**T1:** For these very reasons. Using a mobile phone many, many illiterate people have mobile phones...

**R:** So it's rather not user-friendly for her now...because this is about her.

**T1:** Oh sorry, yes, yes. It's not user-friendly for her she really had no idea of a tape-recorder and she didn't have a mobile phone and that's also where I said the added burden you know of ... using it and pressure yes...kind of now teaching her technology on top of the education regarding her issues that she has to deal with.

**R:** Yes that's interesting ahm...

**T1:** And I know from myself, give me anything technological... however simple [laughs] and I'm considering myself fairly intelligent and literate and I don't even read the information leaflets.

**R:** So ja, and then you said ineffectual in assuring a continuum of service delivery...this is a bit of a difficult one but what I actually meant was ahm...you know that the continuum of service delivery... it's not that you saw her...and then there was this cut off...nothing and then when she comes back then only you know ahm...

**T1:** The strategies is a continuum that's why I always give my telephone number so that they're not at loss...

**R:** ...but for her...

**T1:** ...but for her... she didn't contact me, I didn't hear from her, when she came back, she kind of handed me the tape-recorder as if to say this thing I was given I'm handing back... you know almost... that was my experience like; what do I do with this... so obviously for her it wasn't efficient.

**R:** Ja, I mean I can tell you now what she said to me. I think the reason why it might have seemed like that was probably because I had asked her about it to give it back and then I forgot about it.

**T1:** Yes.

**R:** And I think maybe she was like; must I keep it now or you know...Because what she said to me was that she listened to the thing all the time...

**T1:** Oh did she? Good.

**R:** She said because she was so alone and she couldn't do anything... ahm she started listening...

**T1:** Did it help her?

**R:** She said it was wonderful.

**T1:** Oh great.

**R:** And she said she listened to it in the morning and in the evening and her husband listened with her, but the interesting thing with him was that even though he listened and he might have heard all the information...

**T1:** He was impatient.

**R:** ... ja he was impatient and he didn't want to believe that that is how it's going to be. She said to me; he just shouted at me and he said...

**T1:** They must fix the hole.

**R:** ...they must fix me, I wasn't like this before and...she said he just doesn't want to believe. Doesn't matter how often they listen to it and how often she explains to him...

**T1:** Sure ok.

**R:** So...

**T1:** Great.

**R:** Ja so that basically...what it just showed was that with her in particular, because she was alone, it was actually nice for her to have your voice.

**T1:** Ah.

**R:** Because she says she sits alone the whole day and she can't even read, she can't work...so...

**T1:** So she listened to that but she didn't have access to ...

**R:** The mobile phone.

**T1:** ...to phone me because she wouldn't have a cell...ja

**R:** And then she said to me though that you had phoned once and that...

**T1:** I did.

**R:** ...and that the girl then came and said you know and then apparently she said to that girl; no you must tell [the therapist] everything is fine with me...

**T1:** Ok, yes I did phone. I asked if she was fine, if she was using her voice etc.

**R:** Yes, which is quite interesting because...

**T1:** It wasn't fine...

**R:** It wasn't fine, it was everything *but* fine...

**T1:** Ah.

**R:** ...and it would have been... because I didn't really go into that more because I didn't know who was telling the truth and ... because this girl told me that she had tried to get hold of you and apparently you didn't phone back and everything so...that's just something...

**T1:** I phoned her back that's why I got hold of her.

**R:** Oh so she phoned you first...

**T1:** I phoned and then I think she phoned...look I can't remember but I always reply so...I spoke to her whether it was my call or her call.

**R:** Ja and then, this girl said to me that [the client] did have a problem, that she once came and she was crying and she was holding this thing and showing and whatever, but then...you know why didn't they phone or why...that's just something which I unfortunately never really will find out what happened there.

**T1:** And it is particularly difficult with laryngecs because often you know if she was holding her trachea tube and she couldn't get it in, if the hole had narrowed no amount of you know...

**R:** Ja.

**T1:** ...[not audible] go to the hospital.

**R:** So that would have helped...you could have said...

**T1:** At least to say go somewhere ja...I think it's just very traumatic at this time.

**R:** That's actually something which I wanted to discuss with you ...

**T1:** It's very traumatic. That's why I say it's easier with someone maybe with a voice, it's not as traumatic.

**R:** Ja and it's something also that [another therapist] was saying that often they are so traumatised, because she was talking about you and when you see the clients and whatever, that often you will fit them and then they come back and then nothing happened and then you actually take it out and then after a few months when they are ready, when they feel they are ready, they have excepted it, they can cope with it better, then you will put it back in.

**T1:** Not strictly true, I have to make a judgement call 'cause it does mean that it's a new surgery booking again so it's not that simple. I do...if they are not coping with it now like with her, she has got to wear a tracheostomy tube, she's not going to be able to use her voice despite using it well, 'cause her hole has gotten so small plus she's going to have radiotherapy so she can't use it. I might say, let's get it out because it's already too low and then do it much later but...

**R:** So that's also client specific.

**T1:** ...ja you've got to think. I won't just because they're not using it now do it later...no...I might not push but continuously repetitive, repetitive, repetitive and then so if there is no reason for taking it out, I leave it ...I... might take a longer time.

**R:** Ok, so basically what you are saying is that in the beginning they often have a lot to cope with and that's why...

**T1:** It takes time...even with the insightful clients.

**R:** Ja, do you sometimes then think that, whether they cope very well or not is not really an indication of how well they have understood or remembered, it's rather an indication of it's just too much and they need to...?

**T1:** Yes...and it's for some... I've had...it's hard to predict... I've had illiterate shack dwellers do exceptionally well and I've had high intelligent...white businessmen not do well because they're just depressed because they realise what's going on, so it's unpredictable and for that very reason we tend to fit everyone.

**R:** That's interesting.

**T1:** You kind of have a feel, but it does make it easier if they live in the same town...she had a... because then they can come in for you to do the repetitive kind of work.

**R:** Yes, and if they don't...what do you think we could do then? If they don't live here and you have to do the repetitive thing for them to get better quicker. What do you think we can do? Because I mean we've already tried now having a recording and...

**T1:** Ja this is difficult, because it's disorder...depends on disorders. If it was something...

**R:** Ok but now [not audible] with laryngectomies.

**T1:** With laryngectomies I don't really know. I think if they don't have easy access because they often need medical attention...You know none of the strategies might be superb...because it's not just depending on them. It's not like a dysphagia where you say; remember to put your head down when you swallow! Ahm...there can be infections, there can be small stomas, there can be...prostheses fall out and then what you've taught them is just for if everything is fine. If everything isn't fine they need medical attention so...you know it is hard and then they go to places where it isn't a specialist hospital. This is specialist type of care...so you know tracheoesophageal speech unfortunately needs ENT and Speech Therapy hands on care and it's not a nursing sister or anyone. They can just phone and you can say; well, if you can't get a valve in, leave it, let the tract close or; sister see if you can get a pholese catheter in. It's very hard.

**R:** But at least you know if they then do, you're at least managing still. It's not like with her now where she was sitting on that farm and she nearly suffocated because she didn't say; look I have a problem because... and that was dependent on her. It's not dependent on you, that's dependent on her because she didn't cope...

**T1:** Because you can...so sure she can call for help and [not audible] go to the doctor or whatever.

**R:** ... ja because she didn't come and say; look I'm really struggling. I mean she said to the girl; no tell [the speech therapist] I'm fine...which she obviously wasn't and so in the end it all depends on the client.

**T1:** Yes and it is a contact, it is a contact, so it's not necessarily to maintain the treatment but it's a contact...where to go, what to do.

**R:** Yes, exactly and you are still managing through that...

**T1:** Yes absolutely correct.

**R:** ...yea but then the thing is though that you can do all of this, but with her now it showed that it really depends on the client in the end because...

**T1:** Hm if they ask for help...

**R:** Exactly.

**T1:** ... because everyone gets my telephone number and I try and then just say; if you need me, call, if you go to a hospital and they don't know what to do, call... so there is a telephone number.

**R:** So because that's sort of the feeling that I'm already getting is that, you can really stand on your head, you can do everything that you want...

**T1:** Absolutely.

**R:** ... in the end it really depends on the clients themselves, on things like motivation and insight and understanding; well now I really have a problem, I need to make a plan... and you know not just leaving it.

**T1:** Yes and it's not to say that if it didn't work right away now...she's going to have radiotherapy [not audible] etc. If you had to give her this to go home with *now*, she might use it more.

**R:** That's what I was also thinking. I mean she used it now but... I sort of believe maybe for a different reason, you know I mean it did help her to just to reinforce and for her to understand...

**T1:** Yes.

**R:** ...and but it didn't really help with problem-solving for example or...

**T1:** Yes, so again you know it can be... it might not work, so these strategies might not work in the first instance but also repetitively on an ongoing...

**R:** That is so interesting. I haven't actually thought of that yet.

**T1:** The same as she becomes you know... because with tracheoesophageal speech is a lifelong attachment to a hospital or a therapist and a doctor. If you can't get to a team managing you unfortunately [not audible] prosthesis being refitted. That's the disadvantage of it...then you may as well take it out. So when you say, you know about do I do X, Y, Z, with some clients I ... you know it is difficult, or they have got to travel far and it's an expense. I might take it out but each one gets evaluated. But this kind of thing maybe you know... sitting with her, listening to it, letting her play it out and I'm monitoring how she's doing it, she might get familiar with it. As I've said, it's also a taught thing. You've got to even teach what the value of it is.

**R:** That makes a lot of sense. So...that one you've answered and then you said it's suitable for information review by other health professionals or family members. There you obviously mean because it's a recording, they can listen to it.

**T1:** Hm, of my voice ja.

**R:** Do you think though with other health professionals, if she took this and went to the hospital, maybe not hey? Because then they have to listen to the whole thing...

**T1:** It's unfamiliar. They'd have to...so they look at the diagrams... it'll be unfamiliar. It'll help, they can call... but the same as with her husband. He hasn't had the benefit of knowing what it was all about. He had no pre-op counselling.

**R:** Because she said; you know I showed him with the pictures and everything. I think he probably did sort of understand but two things played a role here. The one was that I think, and you probably can correct me with this, that the counselling that you would obviously give a family member is very different from what you would tell the client.

**T1:** No.

**R:** Or basically you would give the basic information but you would give other information like for example you know; be supportive and that you would obviously give...

**T1:** Yes.

**R:** ... and so this was not included in the tape which is also interesting because, you know is there then a need for that also?

**T1:** Ja, I think it's very hard again I've got insightful, literate people where it's just foreign. F7 neurosurgery ward, a guy has got a tracheo [not audible] the nursing sisters...I put pictures up there then...when it's blocked or plugged, where, what, how I mean it's...I think it's again repetitive. He's [client's husband] got to see her, he's got to see that hole that it can't close, because that's all he's interested in.

**R:** Yea.

**T1:** But this is hard things. Laryngectomy is hard and that's why we say we'll give them a trial and if it is too much, remove it and ... you know let her just cope with the hole in her neck rather than all the other things because now when it leaks and she can't replace it ... she's got to come all the way to Cape Town every time...so you know you've also got to maybe see, this kind of thing is maybe very suitable when it's not such a complex disorder.

**R:** Yea, which is why I'm obviously trialling it on not just one. It will be interesting to see what comes out of that...

**T1:** Hm, so the more complex the disorder, it might... you know I think you've got to define the population that you've used it on. You know, if you've got instructions; do A, B, C, D E... I think it will work really well...straight forward.

**R:** Yea... how do you mean?

**T1:** You know like; hold your baby up, squeeze while he's drinking, stop when he's not, finish within 30 minutes, because then they can remember, but it's not a whole big thing...

**R:** Ja, and that's also why you said you know, it was ineffectual in like getting her to comply because there were things that...she didn't actually follow some of the recommendations.

**T1:** Hm, it's just too much at that new point in time, that acute stage.

**R:** Ja, then you said that generally it was effective in improving health literacy and memory that's increasing the efficacy of treatment. Do you just mean overall...?

**T1:** Well it should be...yes it's an added...it should be an added strategy... it should be...

**R:** So are you motivating that it should be an added strategy or how do you mean...

**T1:** It could be...I don't say it's essential...if it was available I would use it... but it's not necessarily always effectual.

**R:** Ok that makes sense.

**T1:** That's what I'm saying so if it was available I would use it but it's not essential in this person's case...yes in the laryngecs because it's best to just say; phone number - call...because I would repeat the verbal stuff over the telephone.

**R:** Hm so you're basically saying that the idea behind the combination of these strategies you like...you think is effective...is that what you are basically saying? Because for her it was mostly not working but...

**T1:** In general, any strategy that will hopefully facilitate understanding, if it was available can be used...but it does not necessarily mean that it will be effectual for a number of issues.

**R:** Ok that makes sense. Ok and then you said that you are undecided about feeling that the combination of these strategies made a difference in her treatment...I think we basically answered that already...

**T1:** We've covered that...you know it was there but it wasn't really effectual for her.

**R:** Ja, and then you said that you didn't feel that it made her more confident in managing her own health... ahm, basically how we said already also, because she couldn't follow the more important things and understand when she was supposed to phone.

**T1:** Hm.

**R:** Ok, ahm...and then... but ja you did say while we had her in the first consultation, with these strategies, the information we gave was clear and accurate...

**T1:** Hm.

**R:** ... and it was ready for review and you know to improve...but for whatever reason...

**T1:** Hm, because of her trauma and her situation just precluded her benefiting from it.

**R:** Ok, ahm you said that...

**T1:** Anxiety, trauma, adjusting to life outside of the hospital...all those psychosocial issues come into play...

**R:** And for her also probably things like the emotional things...being alone at home, not being able to work...Another big thing for her was money...She was worried about how they were going to live now that she wasn't working...

**T1:** Hm, psychosocial...terrible.

**R:** So it just shows you that *that* is a big thing that you must get past first, you know for them to...

**T1:** Hm, trauma...whatever it is...

**R:** Ja, so that's also why you were saying here that it is probably better for voice disorders or for cleft lip and/or palate where things aren't so...it's not so critical...?

**T1:** They're clearer cut...and it's not so medical...they don't need the medical support team as much...

**R:** Ok that makes sense...

**T1:** I mean, it's traumatic having a baby with a cleft but if it's a healthy baby...if the baby chokes or this or that...they don't really need the support...

**R:** Ja...ok and then you said because the reasons are what we said now...ahm are there any other reasons?... Not really?

**T1:** For?...If it's not working?

**R:** Ja, that it's actually just better for voice and cleft palate...

**T1:** Ja, as I've said I think it's for other disorders that are clear-cut you know like a stutterer for example...reminding him what to do...when you can't write down and you've got strategies to practice...that sort of thing...it's not so medical...for me that would work well.

**R:** And is it because the medical thing makes it just much more complicated and more critical...and involves much more trauma than...

**T1:** Hm, absolutely...and things change...if this, then this...if that happens do that, if it doesn't happen... you know...

**R:** In these medical...

**T1:** Ja well in her for example...you don't need to wear the tube but if you feel the hole is getting smaller then you need to put it...you know it's not leaking now but when it leaks you've got to do that... there's all these changing scenarios...

**R:** Ja, which we did put on the thing...

**T1:** Hm...

**R:** ...but I think what also with the whole thing how we recorded it, there's so much...it might be that she sits there...

**T1:** There's so much...they forget...

**R:** ...and she might just not listen at that moment with like attention and then you know forget where it is...

**T1:** It's a lot of information at a traumatic acute time...

**R:** Ja, so you also noticed that these factors that she had, like you were saying, the support and being scared and being traumatised, that that definitely also had an impact...on the effectiveness...

**T1:** No doubt...

**R:** Ok, so as an improvement to the combination of these strategies, what would you suggest...now with this particular case not for anything else...?

**T1:** I would maybe not have so many strategies, I'd probably just have...most of them have mobile phones... so maybe a mobile phone that you can just say 'call me' and then they can give it to someone else and then you can talk them through because you already know the client so...it's a more two-way rather than...

**R:** Ja, but you know that the strategy was actually supposed to cover two things. The one thing was to cover an opportunity for review and recall of information and the second one was an opportunity for regular contact, which is where the SMS and the telephonic follow-up comes from...

**T1:** Ok...

**R:** So what would you, if you don't like this, what would you suggest for the review and the ... if they can't read...?

**T1:** Ja, because it will be too time consuming to continue talking them...you can't manage a whole caseload...

**R:** I mean what I've gotten from our discussion now is that you know basically the idea behind it you think is quite fine...it's just that with this specific client...

**T1:** Maybe we just have to be selective...the idea is very good but that it's not a blanket technique for all illiterate people and again you know you've got to... that it's a technique that's available to

you, provided A, B, C, D, E...because you want it to facilitate and not impede...So it does, you know, again rely on the therapist or the attending person to select and match...

**R:** So would you have like a complete alternative to this whole thing that you would think would work or...?

**T1:** I haven't given it thought...I'm sorry so I can't say no...you know I mean I haven't been thinking of it...I've dealt with many illiterate people and I know I've just got to you know...explain, explain, and explain and it becomes challenging when they're far apart and sometimes it's you know...unfortunately we lose some...not necessarily death you know... it doesn't work...same as in speech therapy you know stuttering ... doesn't always work...

**R:** Ja, so do you think, I mean if you just like from our discussion now...is there any alternative where you think...maybe you say; look these strategies...we could do without them...it's fine if we just...Because you have the experience you know...?

**T1:** Ok, maybe if we use these strategies it shouldn't just be the talking like we did...there was too much...that the recording should be right at the end where the therapist could sit down and think about what I'm going to say...so maybe I would say to her on that recorder; 'as die ding lek, gebruik die wit stockie, as dit uitval, sit in die lang tube, as die groot gat kleiner word, sit in die krom beisie, as jy dit nie kan doen nie, gaan onmiddelik hospital toe'...so it has to be a thought out, but instruction thing not the general talking...I think the general talking is too much...so that when you record something...that instead of whatever I would have written, because I wouldn't have written everything I've said...when I write, it's thought-out and it's an information sheet...So exactly as I had a summarised information sheet, I would read that onto there...

**R:** Ok great, that makes sense...

**T1:**...and then you can also say to the husband...'friende en mense moet kyk na jou lippe wanneer jy praat'...so whatever you would write, you talk into there. So it's got to be kind of thought of afterwards and then handed to her as I would with written instructions...and I think that was too much then because you recorded the whole session.

**R:** Ja, we sort of did. We did stop and start in-between but it was quite a long...

**T1:** Ja, it was general chatting...so you need the kind of summarised version...and the pertinent statements to come on there, that's what I would do different with these strategies...

**R:** Ok, so you say that overall you had a positive experience with this... why do you say so?

**T1:** Ja, well I think positive in that we have to see what we can do to help illiterate people and to get the message across...so I think don't discount it.

**R:** Ok. So you said that the 'please call me' and the follow-up is actually a good thing to use because they don't have to pay money, it's for free...?

**T1:** Hm.

**R:** ... but when they do have a problem, they know you will phone and they will get in contact with you and it also assures follow-up from your side so that it doesn't just get left.

**T1:** Ja, but it does... it makes them responsible for themselves...

**R:** Yes, which I think is another important factor...

**T1:** Makes them responsible because as healthcare workers you cannot follow up every single one...if you give them an appointment and they don't arrive you can't continue calling them...they have to assume responsibility.

**R:** Yes, which is probably you know this whole thing between...you know I know it's their responsibility but then also...you know there are so many factors that then start playing a role like them being scared or them thinking that they are wasting your time or ...and that's where I'm also struggling with...like when is it our duty to actually phone after them...and when is it their duty to...?

**T1:** I think it depends on the nature of the disorder you are dealing with. I do phone because I need to know what's happened, I'm concerned about things. The baby I know they go monthly to the clinic if there's a problem or if the baby gets sick or things the parent will take them. A voice thing is not the end of the world...I'm not going to run after them because they are hoarse...so it's the nature of the disorder.

**R:** Ok, that makes sense. The last one you said...the whole thing with the interpreter actually also got me thinking...because they are so scarce but ideally...it would be great if you could have them there all the time and that they will actually record it onto the recorder, onto the CD...

**T1:** That's not a problem...

**R:** But then the problem is the phoning...

**T1:** It's the phoning ja, 'phone me' now I can't speak the language, I don't have an interpreter, I would have to then be a delay so it's not an immediate thing and again there's a problem...I could maybe get hold of an interpreter, maybe not...but there is going to be a delay so if things again are medical and important, then you'll have a problem...not so with the others. To do this as I've said before now to the interpreter I would say, 'when it leaks da, da, da...so again it's like having someone interpret a list of instructions...

**R:** Ja, which would probably be a nice thing for them because they can sit at home and ...

**T1:** Hm.

**R:** Ok, and then no other suggestions, for whom else you think it might be useful...?

**T1:** Hm as I've said if it's for anybody you know even just instructions, you know for the simpler things like a... stutterers you know where they just can't remember what to do and you can't write it down, you know it's that...it's almost that procedural type of work that you want them to do...

**R:** Ja,...and any other things that you now thought of that are not related really to the discussion that you want to raise?

**T1:** No I think the important one was I think we didn't do it right, there is too much information just chatting on a session...you need to be selective what you put on there...rather than a chat...because it was long...it was like an hour and a half...and then you can't see the wood from the trees with all the discussion...

**R:** Because I had looked at the tape when we were done and it was sort of in the middle so it was about 15 minutes because one side is 30 minutes...and I hadn't changed it so I didn't record the whole thing it was only when you told me...but I still thought afterwards that...because it still was a lot and I mean 15 minutes of recording is a lot to listen to and to follow, thinking and to remember where it was and stuff...

**T1:** Ja and it needs to be systematic thing to listen to...

**R:** ...ja, which will probably become better like you said...with time...

**T1:** Like I have on my handout, stoma hygiene; to clean your stoma you do this...and when it's blocked you do this, when it leaks you do this...but mine was just chatting. It was all there and it's a little bit too much...

**R:** Ok, is that it ...?

**T1:** Hm...

## Appendix O: Transcript of Interviews conducted in Case Study # Two.

**R** = Researcher

**P2** = Client

... means there was a pause or an omission of irrelevant chat/conversation.

**R:** Did you feel that you wanted to listen to the CD that we gave you?

**P2:** Yes.

**R:** Is it? How many times did you listen to it?

**P2:** Whole day [laughs].

**R:** Really, but did you listen to it more in the beginning or ...?

**P2:** Yes.

**R:** And did you listen to it ...why did you listen to it?

**P2:** I just want to listen how do you keep the baby, how you keep the baby healthy you see...so I feel nice.

**R:** Is it?

**P2:** Hm.

**R:** Because it just gave you a chance to remember again what she said...

**P2:** Ja.

**R:** Ok. When you left us that day, was there anything that you couldn't remember very well? Was there anything...when you left us and you went home, did you think... there was something that I didn't understand and I couldn't remember.

**P2:** No.

**R:** Was there nothing?

**P2:** No. I understand everything.

**R:** You understand everything?

**P2:** Hm.

**R:** But how did the CD then help you?

**P2:** It's nice...

**R:** Is it just nice to listen to or is it nice to understand and remember everything?

**P2:** Yes, ja.

**R:** Ok. Did it also help you to just follow what the Speech Therapist was telling you, you know because she was giving you a lot of tips and recommendations. Did it help you to follow that more?

**P2:** Yes, yes why not.

**R:** Is it? Because there was a lot...

**P2:** Ja.

**R:** Do you think if we didn't give you a CD...would it have been easy also for you to follow still...?

**P2:** Yes, thank you for that [misunderstood question].

**R:** Ja...so the CD was good.

**P2:** Uh.

**R:** And if we didn't give you a CD, if we had not given you the CD...?

**P2:** I forget it [laughs], because every time...I say you forget it, you must remind me ...put in the CD, so I listen the CD.

**R:** Is it? So you would have forgotten if we didn't give you the CD?

**P2:** Yes.

**R:** Ok. And so the CD helped you to just plan for him...

**P2:** Yes.

**R:** ...and to help him with everything that the Speech Therapist said you must do.

**P2:** Hm.

**R:** Ok, and did someone else also listen to the CD?

**P2:** Yes.

**R:** Is it? Who else listened to it?

**P2:** My neighbour.

**R:** Your neighbour...ok and what did she say?

**P2:** She say it's nice, doctor give to you the CD, reminding you every time your baby...they say yes it's nice talk [not audible].

**R:** Is it? So she thought it was nice?

**P2:** Hm.

**R:** And your husband? Did he also listen to it?

**P2:** Hm is happy for my husband to have the CD.

**R:** Is it? How many times did he listen to it?

**P2:** My husband?

**R:** Did he listen with you?

**P2:** Yea.

**R:** Ok. So every time you listen he was also listening?

**P2:** Yea. When he is there at home, I say you must put that CD from the doctor.

**R:** Is it? And did he like it? What did he say about it?

**P2:** He say it's nice. He say also his voice is there...

**R:** Is it? And does he think it was nice to hear the conversation that you had...?

**P2:** Uh.

**R:** ...because you were all talking together...

**P2:** Yes.

**R:** ...and there was a lot of information...

**P2:** Conversation yea...

**R:** ...and the questions...

**P2:** Uh.

**R:** Ok. Did it help you to...the CD when the other people listen to it, did it help you to explain to them what is wrong with him...?

**P2:** Yea.

**R:** Did it also help you?

**P2:** Yea.

**R:** Ok. How else did the CD help you?

**P2:** The CD really, it's nice.

**R:** Can you maybe explain a bit more...is it just because it's nice to listen, you can tell other people...

**P2:** Hmm.

**R:** ...other people can also listen...

**P2:** Ja, even how you...if you have even like this baby...how do you keep the baby...you see?

**R:** Ok. Do you think we should give other people also a CD to take home? Other clients?

**P2:** Yea.

**R:** Why do you say so?

**P2:** Id say you must listen the CD, it's special doctors for the babies. Think it's nice to remind everything you know?

**R:** Ok. Then there was the "please call me".

**P2:** Hmm.

**R:** Did you ever use it? Did you send "please call me" to [the Speech Therapist] once or did you not have to use it?

**P2:** My husband, I think he phone him...

**R:** He phoned her once, was it only that once when he phoned?

**P2:** Yea.

**R:** Did he phone or did he send “please call me”?

**P2:** I think he phoned.

**R:** Ok. So you didn’t really have any [other] problem?

**P2:** Hu uh

**R:** So you didn’t feel like you needed to send “please call me” to [the Speech Therapist]?

**P2:** If I have a problem but I don’t have any problems.

**R:** So you didn’t have problems?

**P2:** Yea. Everything is fine...

**R:** Only if you would have had a problem then you would have ...

**P2:** Yea.

**R:** Ok that’s fine...Do you also think that this is a good thing to give other clients? Other mothers, other fathers, for them to say “please call me”.

**P2:** Yea, if someone I see they need it...

**R:** Because it’s also for free...

**P2:** Ja.

**R:** And do you think there are any problems with the mobile phones?

**P2:** Hu uh.

**R:** Nothing, you think that’s good?

**P2:** Ja.

**R:** Now my last question is...what is your overall feeling with this whole...

**P2:** Hospital?

**R:** ...just say like with the Speech Therapist...

**P2:** No, really nice...

**R:** Are you happy? Ok. And why do you say so? What are the reasons?

**P2:** Because you help me for my baby you see. Me I don’t know if he got [not audible]. But doctor tell me and she show me, she open his mouth and say you must look there...you understand? So that’s why I’m happy.

**R:** So they explained to you everything about the baby...

**P2:** Yea.

**R:** They make sure that you know everything...

**P2:** Yea.

**R:** ...and we made sure that you were also...that you know where to get help...

**P2:** Hmm.

**R:** I think that was also very important for you...

**P2:** Hm.

**R:** ...that you have our number so that you could phone when you have a problem...

**P2:** Ja.

**R:** Because the doctor didn't give his number?

**P2:** Hu uh.

**R:** It was just us?

**P2:** Ja. I never see the doctor, only you and [the Speech Therapist].

**R:** So that was actually good for you...

**P2:** Ja.

**R:** If you have a number that you can phone...

**P2:** Ja and ask my problem. But actually I don't have any problem now.

**R:** You didn't have problems...but it was good for you to know that if you have...you could have phoned us.

**P2:** Hm.

**R:** Is there anything else that you would like to say? With this everything that we did or...?

**P2:** No.

**R= Researcher**

**T2= Therapist**

... means there was a pause or an omission of irrelevant chat/conversation.

**R:** Ok, so the first question which had all these...

**T2:** Hm.

**R:** ...I'm going to go through each of them so that you can just have a chance to explain...so you said that the combination of these strategies for improving health literacy and recall are impractical...why do you think so? ...And I just want to say you can be honest, you don't have to please me, you must say exactly what you feel.

**T2:** Ok, for me it was impractical because I...it takes up a lot of time so...it was easy with you but if I were to go and counsel that specific client...I would need to have this whole system to cut a CD, I would need to find a quiet room so it would cut into my day and it would require a lot of planning so it would...in addition to what I usually do it would be a bit of a...

**R:** Extra burden.

**T2:** Yes.

**R:** Ok. And then you said...you didn't circle anything where it said a waste of time or time well spent...

**T2:** Ja I'm a bit undecided on that...I don't know...I don't know what the client said so I don't know if it was...if they found it useful or...

**R:** Ahm I can tell you they...they found the CD very useful.

**T2:** Really? Ok.

**R:** Ja they listened to it apparently all the time...

**T2:** Oh, really?

**R:** ...I mean I can never say if they're trying to please me or whatever...

**T2:** Yes.

**R:** ... but she was saying the neighbour listened with them and then when the husband was there, they would listen together...

**T2:** Really?

**R:** Whenever they couldn't really remember what was going on they would listen so...

**T2:** Ok.

**R:** ...so that's what they said but you never know.

**T2:** Ok. I think...I don't know if it made a difference to them because I wrote later on that the client wasn't discharged to go home...

**R:** Ja which is a valid point.

**T2:** ...so I don't know if the mom had access to a CD, she wasn't always with the child in hospital so for this particular client...

**R:** Yes.

**T2:** ...that's where I'm commenting on, on my particular client...

**R:** Yes.

**T2:** ...I think if it was a voice client for example where the principles of therapy are more generic and you can carry them over auditorily only but I think with feeding, it's quite difficult, because it's a lot of practical demonstration and sitting and watching and things like that...

**R:** Learning through watching.

**T2:** Yes and sometimes maybe a visual tool would be better. A video but I think that would be just as impractical, because then I'd have to set it up. I don't know how useful especially if someone that doesn't speak English, understand in English and it's out of context, so all those things I've left unsettled are because of that.

**R:** No that's good but I must just find out you know what you, because you have quite valid points. Then also you were undecided about if it's unnecessary/necessary...probably the same reason...?

**T2:** I think so yes.

**R:** Like you explained before...and then you also said culturally appropriate/inappropriate...depends, do you mean with that, that depends on what they have and what they don't have...?

**T2:** Yes.

**R:** ...what they are used to...if they are used to using mobile phones.

**T2:** So depends I think on the client, so for this client it was fine because they did have a CD...

**R:** Is it ok so it was sort of appropriate...

**T2:** ...and they could speak English quite well.

**R:** Yes, I must say now that you're just bringing up the language thing, I thought for the fact that they...I mean they weren't...their English wasn't brilliant...

**T2:** Hm.

**R:** ...but you could still sense how insightful they were...

**T2:** Hm.

**R:** ...and how quickly they...you know...

**T2:** Yes.

**R:** ...I found that was so nice to watch because their English wasn't really like good enough to immediately show...

**T2:** Hm.

**R:** ... but you could see how insightful they were and how well they understood and even with their little English, the questions that they asked...

**T2:** Hm, that's right.

**R:** ...showed you, you know, how...

**T2:** That they had an understanding so with them it was fine but if you have a very low level client who is illiterate, I would be wary of sending them with a CD and I would be uncertain as to whether they really understood...so I'd rather want to be there and I would rather use my phone because then I could talk them through it...ja but anyway carry on.

**R:** Yes... that makes sense. Ok and then you said it was user-friendly because they knew how to work everything...

**T2:** Hm.

**R:** ...and then you said it was unsuitable for information review by other health professionals...with that you probably mean because it was a CD that they can't listen to...?

**T2:** Yes so they didn't have maybe access to it or time whereas if they had a pamphlet it might be easier to give someone and they can just whiz through it.

**R:** Yes the client can give them and say...ja that makes sense. Ok and then you also didn't say whether it was effectual/ineffectual in inducing compliance and behavioural change...

**T2:** Hm...I don't know...so I can't...

**R:** I must also say I was sitting there in the follow-up and I couldn't really say, you know did the CD now really make a difference because they were fine...it could have been that it was because they were able to listen to the CD...

**T2:** Hm.

**R:** ...or it could have been that they just understood from the beginning...

**T2:** Ja so it's difficult to measure that outcome...

**R:** Exactly. Ok then you said you are undecided about if they made a difference in the client's treatment which is probably what we just discussed...

**T2:** Ja.

**R:** ...because we can't really say if...

**T2:** If ja, I can't really measure if the CD made a big difference or if it was just the client...

**R:** Ja just them from the beginning understanding everything and being able to manage it immediately...

**T2:** Hm.

**R:** ...ok but then you said that you do agree that they were more confident in managing their child's health when they had a chance to listen to the CD to review the information and be in contact with you.

**T2:** I think the contact helps. I think it does give people confidence to know that they have all these tools and I think if you leave the doctor with a pack of vitamins and a pamphlet, you feel more equipped. In the end I don't know how much of that you use but the more you give people, I think you do in a sense empower them. So in that sense I think yes they did have more confidence because they knew that I was just a phone call away...

**R:** Yes...and they had a CD where everything was on...

**T2:** Yes so...

**R:** ...so everything that was discussed, even the questions that they asked...because there was one thing where she said her husband quite enjoyed that his questions were on there, he could hear his voice and what you talked about and...

**T2:** Oh.

**R:** ...which is quite interesting because you would never think that it would matter to them to actually hear...

**T2:** Themselves.

**R:** ...yea and what they said and what the answers were and it was quite interesting and I also wrote here that I think it was quite nice that they had your number...

**T2:** Hm.

**R:** ... I think it's a good thing...

**T2:** Hm.

**R:** ...that they know, even if they don't have money they can send a "please call me"...

**T2:** And someone will phone them back.

**R:** ...and someone will phone them back. Ok and then you said that you found that once they had left the consultation the information that they were taking with was clear, accurate and complete but you didn't tick ready for review...

**T2:** Oh...I ticked either or...I suppose it was ready for review.

**R:** Ok...because the CD was basically...covered both of these basically...

**T2:** Ja.

**R:** Ok and then you said you did not feel that these strategies are appropriate for management of dysphagia and then you gave a reason here because it needs more hands-on demonstration...I think that's what you were saying in the beginning...a video would be better...

**T2:** Hm.

**R:** ...because they get to see what you are doing rather than just listening...

**T2:** Ja.

**R:** ...because there is such a ... there is a chance that they might misunderstand...

**T2:** Hm.

**R:** ...is that what you mean?

**T2:** Yes.

**R:** Ok. Then you said...which I thought was a valid point...where you said when the child was discharged, they didn't go home, they were actually in the care of other caregivers and they didn't have...so do you think that there is a need for that, that they should get...either be able to use the "please call me" or your mobile phone number, I mean I don't know what you do. Do you normally give your mobile phone number out to...

**T2:** To some clients I do, I mean all clients have our office hour details but a lot of my laryngectomy clients have my mobile phone number and then paediatric feeding clients, I give my mobile phone number, I mean some adult clients too...it's not routine but if I think they are difficult and they are going to struggle, then I will give it...

**R:** Ja and if they now go like here where they first went to another hospital, do you think the sisters there do you think the sisters there, they would also have a need for...

**T2:** I wrote in the end and I think in the end it might be better to educate other professionals and hopefully with the whole new healthcare plan, there are going to be people at different levels of care and I think equipping them and having a video or CD for nurses at clinics so that there is support there where you have a professional who can guide things and the client is not left by themselves so that they have some...that they are educated more...

**R:** So basically, it's not just at the home that we do this process, there's actually also a need in other facilities...

**T2:** I think so.

**R:** ...that don't have...

**T2:** I think with cleft feeding...it's quite common and the nurses at clinics could assist if it's an easy client, just knowing about the soft bottle whereas nowadays clients get sent with nasogastric tubes because the nurses at those facilities don't know what to do so they send them to us with a tube in

like three months after they had been born so it would be good to try and disseminate information at that level too...

**R:** Ja and do you mean it will be more general information or would it be like a CD for each client?

**T2:** No.

**R:** It must be more general probably.

**T2:** Yes.

**R:** Ok, and then do you think there is a need for them having your number also like personal contact with you?

**T2:** I think nine to five...office hour contact is acceptable, most nurses aren't going to want to phone me after hours unless they're working night shift so if they can get hold of me during the day... that should be enough unless it is a really difficult case.

**R:** Yes ok that makes sense. And then you said as an alternative you would suggest just giving a mobile phone number...why do you say so?

**T2:** Because a CD you need to have access firstly to the equipment, you need to take the time to do it, these people obviously enjoyed hearing themselves so there was an attraction for them but someone else might not be as compliant or motivated. It's the same as a parent who doesn't do therapy with their child. You can't force them to listen to a CD. But it's sometimes easier to just pick up the phone and say help me now, I'm stuck. So it requires more effort on the parents' part and if we are already dealing with people who aren't really that compliant and aren't that literate, it might be more difficult for them to implement that part of the process.

**R:** You mean listening to the CD and making sense of it...?

**T2:** Yes.

**R:** Do you not maybe think that having a CD, which is such a modern thing...maybe that it will actually increase them wanting to comply...?

**T2:** It might...

**R:** ...it's something new and I don't know, I'm just asking what you think?

**T2:** I think of myself, I have CD here that I looked at this morning and thought; I haven't watched that CD yet, and if I had a piece of paper in front of me and I could just quickly read it, it would be easier, because I can carry it around and take it home. You have to make the time, you have to sit down, you have to do it.

**R:** Yea and listen attentively and I mean even because [the recording] it was about ten minutes I think, and I mean if you think of listening to ten minutes of audio recording, it is quite long to sit through, listen, process it, understand make sense of it.

**T2:** Hm.

**R:** And so I think you have a point when you say it really depends on the client and if they have the insight and motivation...

**T2:** Hm, to do it.

**R:** ...because and you were also saying it might be that if they don't have the insight they will listen to it and they might misunderstand which is even worse...

**T2:** Hm.

**R:** ...so it really in the end again the first case study was the same thing, it really depends on the client, I don't think this can be a universal thing that you can use with everyone...

**T2:** No.

**R:** ...it really has to...it depends. And then here like you said before there would be more a need to educate the community caregivers...like sisters because they are more available to everyone...

**T2:** Hm.

**R:** ...and then you said you disagreed that you had a negative experience using these three strategies, can you maybe just explain a little bit more?

**T2:** I didn't really bother...I didn't find it a problem. I did write in the next paragraph though that I found it...it was difficult when they phoned me about another problem, and that's the danger...

**R:** Yes, ok tell me a little bit about that.

**T2:** The parents, it was that evening where the baby was still in hospital and the child was constipated and was in pain and nobody had helped the child the whole day so it was eight o'clock at night and the father phoned me frantically or I phoned him back and he said; please help me the doctor is not coming and the nurses are rude and his wife is in a state...and this is not my area and now I have to sort it out and in the end I had to speak to the sister and I had to make sure that the doctor was going to come and see the baby. So because you are making yourself responsible for one aspect of care, the client doesn't understand that you aren't a doctor and they might generalise it and think you are responsible for everything, and that dad wanted...I had to help him and if I had said to him I'm sorry I cant help you I would have felt really bad and very responsible if something had happened...because I have more insight than him and so I should do something, he's handed the problem over to me now and that makes it difficult...

**R:** So that [handing out number] increases the chance of you being in situations like these where clients will phone you...?

**T2:** Definitely, you are making yourself accessible so they ... and a lot of clients don't realise that you are only the Speech Therapist, they think that you are the doctor or the nurse, a lot of the clients here they come with other problems too.

**R:** It's so difficult...because on the one hand you want to give them a number so that if they really have a problem concerning you...because you also don't want them to sit at home and struggle with what is your area of expertise...

**T2:** Yes.

**R:** ...but then this happens.

**T2:** I think it's how far do you want to extend yourself, how much control do you want as a therapist...for me I feel I don't want to...I don't want him to listen to a CD, I'd like to still be in control and that's my issue probably...I would like to manage it verbally or with some kind of personal contact but on the other hand you can't extend into other fields and they were sitting in a hospital and they were phoning me to help them with their baby. So... there were lots of other medical professionals around them, it wasn't that they were isolated at home and they didn't know what to do at eight o'clock at night, they were sitting with nurses and doctors and saying you must help us...

**R:** Yea so you are saying that you prefer to rather be in personal contact with them should they have a problem...?

**T2:** Hm.

**R:** ...but then there's still...

**T2:** I think this is the risk of giving it, and probably the risk that everybody has. But it is hard at eight o'clock at night to now be responsible for the child's health when it's not your area so... but it's fine...

**R:** It is quite...and I really get your point there because no matter what strategy you decide on there will always be some problem and I think in the end it depends on each therapist themselves...what can they tolerate and what can't they...

**T2:** Hm.

**R:** ...again it shows that this is not something that is universal...

**T2:** I think the cases that you've chosen to use this with, I would maybe use it with more benign cases like artic. I would give the mother an artic CD so that she can listen to it. I would maybe record a session where they can do the therapy and I would maybe find that more useful but these things... A lot of these clients are quite... like dysphagia, the client would be acute, a laryngectomy client could inspire their valve, so you are dealing with more medical cases in your study and that

makes these clients maybe more prone to phoning you whereas a mother with a child who has artic problems, if the child gets a middle ear infection... so what you can sort it out tomorrow.

**R:** So she would have to listen to a CD and quickly catch up with what she had forgotten...?

**T2:** Yes to actually implement the therapy and you're going to have to sit for half an hour with your child anyway and... I don't know if I would use it in these types of cases.

**R:** No you have a point there. And then you said that it was not useful for people who don't have sufficient English language skills. Is that because we didn't have an interpreter there?

**T2:** Hm.

**R:** And you didn't have an interpreter when they phoned...?

**T2:** Ja I think so. I think it is going to be difficult if you don't understand the client. It is bad enough when they are sitting in front of you and you need to have something in their language, that's the ideal so again I would worry about them misinterpreting and...

**R:** Even though their understanding of the English language was not disastrous...

**T2:** Hm.

**R:** I also still think that in the end, they will open up more and they will understand more if there is someone that speaks their language...

**T2:** Hm.

**R:** ...even though they may get the gist of it...which also then makes me think; should I have had someone there but I also thought that from the beginning, the husband actually came across as quite well spoken...

**T2:** They were quite...ja.

**R:** ...but I still thought at the end maybe I should have had someone there...

**T2:** I think they were fairly... it was fine with them, but if you have someone with a lower level of English it is going to be...you definitely need someone to interpret because otherwise it is going to be a waste of time.

**R:** Ok and then your last was...it may be difficult for clients to make sense of the info when it's out of context so they are not here, they can't quickly ask a question...

**T2:** Ja they can't clarify things and if they misunderstand they implement the wrong feeding technique or whatever...there is no one there to correct them...

**R:** Ok and a time delay has followed, what do you mean with that?

**T2:** They have left, it is the same as you saying I need to interview you quickly so that you can remember what happened. They've also left so they might not remember what we were talking

about and because it is out of context, they might not know what I was applying to if I say; and look when you do it like this... they might not remember *this*.

**R:** Ok I get that ... and then you said; also you are relying on the client to make use of CD vs. mobile phone, one option might just be easier to use...

**T2:** Hm like a "please call me".

**R:** But these were actually, they belong together it wasn't either or but you say it should rather be...

**T2:** The client may just choose one...I don't know they might just think; oh well the child is struggling right now, I can't go and listen to ten minutes of CD because he is busy choking now, let me just phone...so it is almost quicker and easier...

**R:** Ok that makes sense...that's it.

**T2:** All right.

University of Cape Town

## **Appendix P: Transcript of Interviews conducted in Case Study # Three.**

**R** = Researcher

**P3** = Client

**C3** = Caregiver

... means there was a pause or an omission of irrelevant chat/conversation.

**R:** Ok, so die eerste vraag is...het julle die gevoel gehad dat julle na die tapie wou geluister het?

**C3:** Ja, ja.

**R:** Is dit? En wanneer het julle gevoel dat julle daarna wou luister?

**C3:** As ek uit die werk uit gekom het...toe ons by die huis kom, het ek vir sy suster die tapie gespeel, om vir haar te laat luister wat alles aangaan, en dan speel ek dit hier by die huis ook om dit net bietjie vars in my geheue te laat kom.

**R:** Is dit? Ok, en meneer?

**P3:** [not audible]... sy sê ek moet vir haar wag [not audible].

**R:** Ok, so wat sê meneer? Meneer het saam gegaan?

**P3:** Saam geluister!

**R:** Oo, saam geluister toe mevrou geluister het?

**P3:** Ja.

**R:** Ok, en hoeveel keer het meneer daarna geluister?

**P3:** So drie keer.

**R:** So drie keer ok. En die dag toe julle mos van ons weg gegaan het, was daar enige iets wat julle nie verstaan het nie of nie kon onthou nie?

**C3:** Nee, ek het alles onthou en verstaan.

**P3:** Glad nie...

**R:** Glad nie...[julle het] alles verstaan en onthou, ok. Dink julle dat die tapie vir julle gehelp het om die goed...want sy het mos vir julle die prentjies gegee en die informasie op geskryf in 'point-form', maar het die tape gehelp net met om alles nog 1 keer bietjie mooi te verduidelik en...want op die tapie het sy mos alles nog in detail...

**C3:** Ja.

**R:** ...meer verduidelik. Het die tapie daarmee gehelp?

**P3:** Die tapie het baie gehelp want ons sal vergeet het.

**R:** Is dit? Ok, maar sou julle nog steeds vergeet het saam met die prentjie en die wat geskryf was?

**C3:** Hm.

**P3:** Ja.

**R:** Ok so die prentjies en die geskryfde het gehelp maar die tapie het gehelp...

**C3:** Dit het dit net n bietjie meer duidelikheid gegee. Die tapie gee meer duidelikheid.

**R:** Ok, dit is goed. So dit het vir jou gehelp om te vetsaan...?

**C3:** Ja.

**R:**... om nog bietjie meer te verstaan en vir jou [client] ook gehelp om te herinner hoe spesifiek jy die 'exercises' moet doen en...

**P3:** Ja, dit het baie gehelp, daardie tapie het baie gehelp.

**R:** Ok, het julle na die prentjies en so ook gekyk terwyl julle geluister het?

**P3:** Hm.

**R:** Is dit? Ok, en het iemand anders ook na die tapie geluister? Mevrou het gesê...

**C3:** Ja, sy suster het geluister, en dan het die klonkie ook geluister...

**R:** Ok.

**C3:**...die enekie van my.

**R:** Is dit?

**C3:** Hy het nou gister aand weer die tapie aan gesit om te luister.

**R:** Is dit? En wat het hy gesê daarvoor?

**C3:** [laughs] Hy het niks gesê nie...hy het net geluister.

**R:** Is dit? Sê hy nie; oo dit is interessant of...

**C3:** Hu uh.

**R:** Maar dink mevrou dit het vir hom ook bietjie gehelp om te verstaan wat sy pa moet doen en so of...hoe dink mevrou het dit vir hom bietjie gehelp?

**C3:** Hulle is maar nou net...hy het geluister...soos ek nou kan sien is hulle maar net bewus wat aangaan...

**R:** Is dit?

**C3:** ...so vat ek dit nou.

**R:** Ok. Het hulle na die prentjies ook gegyk?

**C3:** Nee.

**R:** Is dit? So dit help bietjie om net vir hulle soos mevrou gesê het, bewus te maak oor wat hy [the client] moet doen en wat hulle pa moet doen?

**C3:** Hmm.

**P3:** Hm. Dit help baie.

**R:** Is dit?

**P3:** Sy help baie. Hy help nie met die [not audible]. Daarvoor is die vrou daar. Hy sê daarvoor is die vrou daar om te help met...

**R:** Is dit? Met wat?

**C3:** Met die oeffeninge.

**R:** Is dit? So hy help nie met die oeffeninge nie maar...

**C3:** Maar hy sit dan by...

**R:** Is dit, ok goed. En die suster...wat het sy daarvoor gesê, oor die tapie?

**C3:** Sy het gevra, wat is dit? Toe sê ek dit is die oeffeninge wat hy elke slag kry vir sy mond om sy spraak te laat bykom, tongoeffeninge en alles.

**R:** En het sy enige iets gesê oor wat sy daarvoor dink oor die tapie of...?

**C3:** Nee sy het nou gesê dit is iets goed, vir die vergeetslag.

**R:** Ok mooi. Ek kry ook die gevoel, dat die tapie het vir julle miskien bietjie gehelp om vir die ander mense ook te verduidelik wat aangaan...?

**C3:** Hm.

**R:** ...want as julle mos nou net die prentjies gehad het, dan sou dit miskien n bietjie moeilik gewees het vir die ander mense om rerig te verstaan.

**C3:** Wat aangaan...

**R:** Hm...maar so julle het vir die seuntjie en vir die suster die tapie gewys...?

**C3:** Ek het die tapie werk toe ook geneem om vir hulle te gaan speel het...en hulle het vir my gevra; wat is dit? Toe sê ek, dit is die sessie wat hy gehaad het by die spraakterapeut...

**R:** Is dit?

**C3:** Ek het dit werk toe geneem.

**R:** En wat het hulle gesê?

**C3:** Nee, hulle het gesê hy praat baie beter, want hulle het nog laas vir hom in die hospitaal gehoor praat.

**R:** Is dit? So dit was miskien ook mooi om net vir die mense waarvoor julle werk, om te wys wat gaan aan in julle lewe en wat sê die spraakterapeut en...

**C3:** Ja.

**R:** En het hulle enige iets anders nog daarvoor gesê oor die tapie?

**C3:** Hu uh.

**R:** Nie rerig nie. Ok, dink julle ons moet hierdie tapie vir ander pasiënte ook gee om huis toe te vat?

**C3:** Dit sal goed wees ja.

**P3:** Ja.

**R:** En hoekom dink julle so?

**C3:** Kyk ons kry mos nou die oeffeninge, maar die is mos nou n prentjie wat hier op is, die prentjie kan mos nie praat nie, maar as dit soo...die pasiënt en die spraakterapeut praat met mekaar. Sy verduidelik vir hom wat aangaan en nou doen hy dit. Daar is meer n verstandhouding...sien daar is meer n verstandhouding tussen die twee, want dit word gedoen en dan word hy mos nou hierop gespeel. Nou ander mense wat luister daarna...dit is mos nou iets werklikheid wat mos nou plaasvind.

**R:** En hulle kan dit volg...?

**C3:** Ja.

**R:** Ok dit maak baie sin. En het julle ooit die gevoel gehad dat julle n "please call me" wou gestuur het?

**P3:** Sy wou graag gehad het...

**C3:** My foon is mos weg maar ek hou nie van so baie mense pla nie, maar ek het vir sy suster gesê, sy moet die "please call me" stuur, maar ek het nie daarbei gekom om die nommer vir haar te gee nie. Want toe mevrou hulle vir my kom soek, toe was ek by die huis. Ek het vir hulle gesê ek gaan werk...maar ek het nie gaan werk nie...hulle [family] het my kwaad gemaak. Hulle het my kwaad gemaak en toe loop ek en toe gee ek in die dorp in antwoord.

**R:** Ok so wanneer wou jy graag n "please call me" gestuur het?

**C3:** Ons moes mos by die hospitaal gewees het...en toe reen dit mos.

**R:** Ok is dit die dag toe jy graag wou gestuur het?

**C3:** Ja maar, as ons n geleentheid kry vir hospitaal toe, maar die meeste van die tye moet ek vir hom stoot tot daar in die kaarritjie, ek kan nie vir hom stoot as dit reen nie.

**R:** Ja ek verstaan dit. Nee dit is ook ek het nie n probleem daarmee [that they could not make it]. Maar was daar enige tye waar julle n probleem gehaad het met die 'exercises' of toe hy geëet het of so, waar julle gedink het; agh ek sou so graag nou vir haar bel!

**C3:** Nee, ek het vir sy suster gesê omdat hy mos nou heel dag by haar is, toe het ek vir haar gesê as hy nou eet en hy verstik en dit is te aanmekaar, dan moet sy die nommer net "please call me" en dan moet sy die nommer stuur. Want sy het vir my gevra vir wat is die nommer, toe verduidelik ek mos nou vir haar.

**R:** Ok het jy...ok so het sy die nommer gehad...of jy het hom nie vir haar op geskryf nie maar het jy vir haar verduidelik...

**C3:** Ek het vir haar verduidelik...ek het die nommer...want sy het vir my gevra vir wat is dit nou alles toe sê ek nee...is mos nou by die kos as hy eet en hy verstik nou te aanmekaar...dan kan sy n "please call me" stuur, dan sal hulle nou vir haar...

**R:** Ok en sy sou dan vir jou gebel het [at work] en dan kon jy dit vir haar gegee het...die nommer...

**C3:** Ja.

**R:** Ok, was daar enige tye toe sy graag wou gebel het...meneer kan meneer onthou toe...was daar enige tye toe meneer graag vir haar [speech therapist] wou gebel het toe daar probleme was?

**P3:** Alles het goed verloop.

**R:** Het alles goed verloop?

**P3:** Die kos en die water...dit het goed gegaan...soos sy verduidelik het.

**R:** Ok. En so dink julle dit is n goeie ding om hierdie "please call me" te hê?

**C3:** Ja want in die begin [right after the assault] het ek baie paniekerig geraak, as hy so aanmekaar verstik het...dan het ek ook myself gevra...wat gaan dan nou aan?

**R:** Hm, en dit is seker ook moeilik as n mens nie geld het om nou te bel nie en dan sit n mens hier en n mens kan nie bel nie...maar die man het n probleem en dit is seker dan baie 'convenient' as n mens weet mens kan n "please call me" stuur en iemand sal terug bel.

**C3:** Hm.

**R:** Ok, nou weer...dink julle dit is n goeie ding om vir ander pasiënte ook te gee? Die "please call me"?

**C3:** Ja.

**R:** Ok en dit is hoekom?

**C3:** Kyk hy het mos nou, ek sal sê in die begin het ons baie gesukkel met hom...en hoe kan ek nou sê...die kos het uit die mond uitgeval...ons het mos nog nie oeffeninge...dit is mos na die tyd wat ons gegaan het vir terapie...en dit is na die tyd wat hy die spraak gekry het...hy het mos nie dadelik spraakterapie gekry nie...ons het maar net gegaan vir die fisio elke slag...en die spraak...ek het altyd gedink; gaan dit nou reg kom of so, sy spraak was baie swak gewees...Daar was n probleem met die eet gewees, daar was n probleem met die drink gewees, dit was baie swaar gewees en as ek nou in die begin die pad geloop het saam met hulle [all therapists], dan sou dit nou vir my beter uitgewerk het.

**R:** So as julle van die begin af hierdie en die 'please call me' sou gehaad het en die prentjies en so wat sy gegee het...

**C3:** Ja.

**R:** ...sou dit bietjie makliker gewees het...?

**C3:** Ja.

**R:** ... is dit omdat julle dan n bietjie meer 'safe' gevoel het...want julle het al hierdie goed en as julle n probleem het weet julle...

**C3:** Wat om te doen, ja.

**R:** Ok. Hoe was julle hele 'experience' nou met die spraak terapeut? Alles wat ons nou gedoen het...hoe voel julle nou 'generally' daaroor?

**C3:** Vir my is dit iets goed want dit help vir hom en as hy gehelp kan word en hy vorder, dan is ek tevrede...ek is bly daaroor...Dit is iets goed want as hy nou nie die spraak gekry het nie dan het hy mos dan nou gesukkel om van self want...kyk ek kan hom gehelp het maar ek kan hom nie so gehelp het soos julle my vir hom help nie.

**R:** Ja ok. En ek kry ook die gevoel dat as julle...Julle het die prentjies gehad en wat [the speech therapist] opgeskryf het en julle het die tapie gehad en "please call me" en n nommer...en ek kry die gevoel as julle dit het om huis toe te vat...dit voel net beter...dit voel julle het iets wat vir julle...waar julle na kan terug gaan en weer lees en weer luister...

**C3:** Ja.

**P3:** Hm.

**R:** ... en as julle n probleem het kan julle in kontak kom...dit voel net meer 'safe'...is dit nie so nie?

**P3:** Hm.

**C3:** Ja. Ek het nog altyd die ander oefeninge ook van die spraak en as ek so deur die blaie...en ek luister na sy spraak en ek sien maar hier is iets nie lekker nie dan kan ek weer terug gaan en vir hom help weer daarby.

**R:** Ja so dit is baie belangrik dat julle iets kry wat julle kan huis toe vat omdat soos jy sê dit is vir jou om te sit en weer te luister en weer te lees en...

**C3:** Hm.

**P3:** Ja.

**R:** Ok, is daar enige iets anders wat julle nog graag wil sê oor wat ons hier gedoen het en...?

**C3:** Ek is maar net bly vir die hulp wat ek ontvang en as dit vir hom kan beter maak dan is ek bly daarvoor.

**R:** Ok, en meneer?

**P3:** Dit is eers goed wat julle doen.

**R:** Is dit?

**P3:** Ja ek sê baie dankie wat julle vir my gegee het en wat julle gedoen het.

**R:** So meneer sê dankie dat ons al hierdie dinge vir meneer gedoen het?

**P3:** Ja, dit help baie.

**R** = **Researcher**

**T3** = **Therapist**

... means there was a pause or an omission of irrelevant chat/conversation.

**R:** The first thing that you said was that you felt that the combined strategies were practical...

**T3:** Hm.

**R:** ...why do you think so?

**T3:** I think it was practical because of what...the recording that was made was accessible for them, they could switch it on and off at any time that they wanted and they could review the information all of the time so I think it was quite fine for the setting in which they were...The only problem that I had was that the lady lost her mobile phone and she wasn't able to contact me with a "please call me" but other than that I think it was quite effective for their setting.

**R:** Ok, and you said it was time well spent is that exactly because of that...?

**T3:** Yes.

**R:** ...because we provided them with something that was practical and appropriate and...

**T3:** Hm, yes and I don't think it was a waste of time because we didn't actually use extra time with this. We just used the therapy time that was already set out before.

**R:** Ok and you said it was necessary, why do you think so?

**T3:** I think that the client has to have something that they take home, because often I find that therapists give clients recommendations and they give them different exercises to do and so forth and they don't send the client home with something because by the time they get home, they have forgotten what they have done in therapy and by the time you get to them, then they haven't done the exercises, not because they don't know how to do the exercises but because there wasn't a strategy for them to remember it. So I think this is actually really a good way of doing it as well.

**R:** Ok, then you said they were culturally appropriate, can you explain a bit more what you mean?

**T3:** Yes, I think it was culturally appropriate because they used a tape, you know...

**R:** They know what it is ja.

**T3:** ... and a tape is what they know. I know the dictaphone is a bit culturally inappropriate...

**R:** Ja.

**T3:** ...but they have the concept...

**R:** The concept.

**T3:** ... of having a tape or a CD-player...that was fine. My only issue would have been if they did not have...if we didn't have the dictaphone to give them or if they...with their case they don't have a CD-player...

**R:** Hm they didn't have a CD-player and remember you said that they have a radio but when I was there in their house and I looked it was actually just a small Eveready Radio...

**T3:** Hm.

**R:** ...which just receives... there was nothing that you could put in. And it was quite funny when we were sitting there now today, there was a VCR machine...

**T3:** Hm.

**R:** ...but no TV...

**T3:** Hm.

**R:** ...and it was quite interesting you know they have bits and pieces...

**T3:** Yes.

**R:** ...but nothing that will actually function...

**T3:** Yes, ja so I think with people that are very poor that wouldn't have a CD-player or don't have a tape-recorder, it would have been harder, you know...

**R:** Hm. I think his sister did have one...

**T3:** Hm.

**R:** ...I mean it would have been ok if he could have gone because he is by his sister anyway the whole day so I think it does help if they have a neighbour but then obviously you would then have to make sure of that before...

**T3:** Yes.

**R:** And I also still think, you know... it empowers them so much more if they have the thing with them in their house...

**T3:** Yes.

**R:** ...rather than always having to go to someone else's house or even though they spend a lot of time there...you know always having to go to someone else's house, using someone else's phone, I could see she was uncomfortable with the whole phone story and it was unfortunate you know that she didn't have a mobile phone of her own.

**T3:** Yes and I feel that these resources should be accessible to the clients. It is a great idea...

**R:** You think so?

**T3:** ...you know to have this but we've just got to keep in mind, these clients are here in the suburbs so it would be easy for them even if it is an issue to get it from a client, from a neighbour or from a

family member, they still have it in their environment but if we go more rural to the farms and you see maybe one of my farm clients, they don't have anything there. They don't have the TV, and they don't have the CD-player there so in terms of accessibility it would have been really a big issue.

**R:** Hm and you know what was so interesting...when I first started out with this whole study, I thought you know even our workers on our farm have a sound system there. They have their little house but they have a big thing you know...

**T3:** Yes.

**R:** ...and I thought you know nowadays, I mean if you go to Game you can buy this little round CD-thing with a radio and a CD-player on top for 250R you know and a lot of times I've seen in Namibia a lot you know in the shacks and stuff, people in Namibia love their music and they have it everywhere there is tapes or you know but I've noticed here that it is actually not the case, that people here, I mean I've had another participant that they didn't have anything... you know and so I really do get your point there that it's...the more rural you go here, the more difficult it will be and even though it's a good idea, the objects that we use for the idea are then not always appropriate and you would have to figure something else out.

**T3:** Yes modify it somehow.

**R:** Yes, then you said it was user-friendly...

**T3:** Yes, because it is something that they know, then it's user-friendly, it's not you know if it was something that they didn't know, if you had to give them something else...if you would have given them an i-pod...

**R:** DVD or i-pod yes.

**T3:** ...if you would have given them an i-pod, they would have struggled with the i-pod you know but this is something that they know and I mean the tape is old-fashioned so most people would know what to do with it so it's user-friendly.

**R:** Ok great. Then you said it was ineffectual in assuring continued contact and service-delivery... that was probably because of the mobile phone problem?

**T3:** Hm it was definitely about that.

**R:** I mean it was interesting because she could have sent the "please call me" I mean it wouldn't have cost anything but she still felt uncomfortable when having to ask her husband's sister to use the phone for that and it was quite interesting that...

**T3:** Yes and also the other thing is we don't know what issues there might be between her and the sister...

**R:** Exactly.

**T3:** ...you know so there are also extra factors that you've got to look at when you look at the whole situation because obviously he is at the sister's house during the day and she is dependant on the sister to look after her husband and now she is maybe thinking; if I'm going to use her mobile phone, I'm going to overload her and burden her with another thing... you know so often the clients feel that way when they have got to constantly ask for things from other people.

**R:** That's interesting yes that makes sense. Ok and then you said it was however suitable for information review by other health professionals because...?

**T3:** Yes because I think these strategies could be of assistance when clients are handed over...especially when there are team interventions because all the information is right there with the client and it could also serve as evidence for medico-legal cases.

**R:** Ok, interesting...those are some very interesting points you just made. And then you said it was suitable for other family members, they could look at the pictures, your written recommendations, listen to...it was actually nice that she...that the son listened to it, the sister listened to it...

**T3:** Yes and her colleagues yes...

**R:** ...I thought that was quite interesting.

**T3:** Yea I think she was actually quite enthusiastic about it you know...

**R:** Yea I was surprised I must say...

**T3:** Hm.

**R:** Then you said it was effective in inducing compliance or behavioural change...

**T3:** Yes, I definitely think it was, because what I often find is that... The client seemed like he had more resources to work with, he was more motivated to do his task... He was more motivated because he could take ownership and responsibility for his therapy because he had something in his hand you know to look back at and to refer back to all the time. So for me I feel that now where you actually give the client a tape or you give the client the page then it's them taking the responsibility and saying; ok I need to work on my thing now. So I think it's quite beneficial because if the clients leave without something, then I often find that they forget everything and they don't take that responsibility.

**R:** Yes, they are just more equipped...

**T3:** Hm.

**R:** ...you know and that is why I was saying with them also, I was saying; the feeling that I get for you is that it was nice for you that you had three things, you had a whole lot of papers and written things, you had a tape that was yours that you could listen to and you the chance to send a free message and get in contact with someone and it must be so nice to feel so equipped you know...

**T3:** Hm.

**R:** ...you have all these options and you know when you have a problem, this is what I can do rather than sitting there at home, having nothing and not knowing; what on earth am I supposed to do now? I don't remember exactly what she said, is this what she said and then the sister comes and she is like; I don't know what to do with him during the day...

**T3:** Yes, and I think it is also good from a therapist's point of view because then at least you know you have done all that you could do for this client and at the end of the day it is the client's responsibility to sort it out. Then at least you know when the client comes back, I have given the client all of these resources so at the end of the day it is up to his motivation for therapy and then at least I know; ok well with all of these resources I see that the client is encouraged and motivated to do his exercises or not.

**R:** Yes, and basically this whole thing of continued service delivery, I mean through this you are ensuring that there is a continuous thing, it is not that they go home they have nothing they, they can't really get into contact with you, it's cut-off and they only come back again after a few weeks time... that's when you pick up again...

**T3:** Yes.

**R:** ...Now they go home, they have this, you know that you have continued service delivery but at the same time it still puts some responsibility into the client's hands...

**T3:** Hm.

**R:** ...which I think you know especially in...I find there is this culture especially in South Africa, it was also in some of the research articles...that it's this just receiving but then not knowing what to do with themselves, receiving all this information but then being stuck with...

**T3:** Hm.

**R:** ...the insight and problem-solving, all of that...

**T3:** Hm.

**R:** ...so you know you've done continued service delivery but in the end it really depends on the client...

**T3:** Hm.

**R:** ...I mean you can stand on your head, it doesn't help if they don't have the motivation...

**T3:** Hm that's very true.

**R:** And then you said it was generally effective in improving health literacy and recall thus increasing the efficacy of treatment which is basically what we've just discussed.

**T3:** Hm yes definitely.

**R:** Then you said that you felt that using the strategies made a difference in the success of the client's treatment, I think we sort of discussed that already.

**T3:** Yes we have.

**R:** And then you felt that the client and the caregiver were more confident in managing the health of this man when they had a chance to review the information and get in contact with you...

**T3:** Hm.

**R:** ... like we said, they felt equipped.

**T3:** Yes.

**R:** Then you said...

**T3:** And you know I also feel that they were interacting with the information much better than other clients would have...

**R:** Is it?

**T3:** ...because I find that other clients would maybe give you the information but not necessarily be able to recall it that automatically whereas when I arrived there and I asked him; 'meneer wat is jou oeffeninge'? He could do them off his fingertips, which meant that because he had listened to the information so many times and read through it or looked at the pictures so many times, it just showed me that just the way they were interacting with the information is also quite good as well...

**R:** Yes. I also felt that it was definitely...the whole way that they went about this was...it looked to me like they knew what they were doing...

**T3:** Hm.

**R:** ...it wasn't that the tape was just left there...

**T3:** Yes.

**R:** I mean, the fact that she has all those papers in her bag that she carries around every day says something, you know it is not stuck somewhere in some cupboard or she first has to go and look for them, I mean...

**T3:** Yes.

**R:** ...every time we saw them she immediately took out everything she got which is a good sign...

**T3:** Yes of course.

**R:** And then you didn't tick anything for where the strategies would be most appropriate. Do you think they are not appropriate for any of these or for all of them?

**T3:** I think they are appropriate for all of them.

**R:** Ok and so for reasons you say that these clients need to give feedback in order to guide the therapy process, what do you mean with that?

**T3:** Especially with the dysphagia clients, I noticed that they often recover quickly or they have different problems. The next time you see them something else pops up so it's different things happen all the time with these clients so I feel they need to be monitored closely because maybe on the first day you see that your aims are specific and then the next time that you see them the aims are different because maybe the disorder has changed, there has been spontaneous recovery, there has been some regression. So, in order for my therapy process to be guided, I need to get that constant feedback from the client all the time.

**R:** Hm so you think that's where the "please call me" comes in?

**T3:** Yes, I definitely feel that that's where it comes in because especially when the caregivers are distressed about how they are going to sort the client out, then at least they have got that resource and they can at least say; 'give me a call' and just let me know, then I can give them that compensatory strategy immediately or do a home visit or do whatever needs to be done for that client.

**R:** Yes and I think so also because it's quite interesting because you are the first one that actually points that one out. I mean other therapists have said that the "please call me" and the follow up is the most important but they are not so sure about the recording...

**T3:** Hm.

**R:** ...but I find that how you are saying now is...the "please call me" I think is a really important thing...

**T3:** Hm.

**R:** ...because it is this regular contact like you were explaining that is really needed because...and that is also what the other therapists were saying that the disorders keep changing...

**T3:** Yes it's true.

**R:** ...things keep changing all the time...I mean it's the same with dysphagia, with voice not so much but with these three, things keep changing and you have to have that contact but for some reason it's not happening.

**T3:** Hm and I feel worried that clients get lost in the system. I feel worried that their disorder might change and they get lost in the system and then who does the follow-up, if we aren't there to do the follow-up for them? So it becomes a critical issue.

**R:** Yes I think that's where this whole issue comes in with continued service delivery because yes you've seen the client, you've done your best, you are sending the client home but what happens in that time? Things change, they need different help...

**T3:** Hm.

**R:** Not all of them do but the one's that do...what's wrong with them having a chance to get in contact with you, sort them out quickly and there you go...

**T3:** Yes I'm glad that you actually have it on an out-patient basis because very often these clients are being seen at an in-patient basis. They are being seen intensively at the hospitals and then once they are being discharged from the hospitals they aren't being seen as often. So, follow-up isn't done as regularly so I think that that time frame...if we were in a tertiary hospital we wouldn't have had this issue because we see the client every day but in our out-patients setting, I feel that it is needed because you don't see the client all the time.

**R:** Yes definitely. And then you also said that there is place for clients to relearn and remember aims...do you mean with our written and pictures and with this...?

**T3:** Yes a combination of everything...

**R:** Even though like you said especially with dysphagia, things change...

**T3:** Hm.

**R:** ...it still is nice for them to sort of go back to; ok this is where we were last time but now I have this problem, maybe now is the time to get in contact with the Speech Therapist or...

**T3:** Hm, yes.

**R:** And then you said it would also be beneficial especially post-op when clients are worried and distressed.

**T3:** Hm.

**R:** That's an interesting point that you made there...

**T3:** Hm.

**R:** It's so interesting because in the literature review they were saying a lot about that. They come here and they are so emotional, they can't take in anything.

**T3:** Yes and what I often notice is that especially with my adult clients that I see here, most of the time they are coming from the hospital and they have just been discharged where the doctor has done many tests on them, they have been seen by different people and now they are left here at an out-patient institution and now they have got no idea what has happened to them, what doctors have done to them. They had a traumatic experience, they are having difficulty, they can't go to work anymore, issues with the families, social difficulties, they are overloaded by the time they get here. Half the clients start weeping in my session if I just ask them; how are you? What has been happening in your life in the past week? So, it's quite difficult for a lot of them...to have operations and strokes and those type of things and experience the dysphagia and that and I also feel that at the end of the day, with the way that the health system is right now, us as therapists are the people that

end up informing the clients as to what their diagnoses are, what operations have been done to them, what was the intervention so far. We do a lot of the educating happens here and which means that we have to be sensitive to those clients and available for those clients so if that client sends me that 'call me' then at least I know; ok I can sort the client out because the client was stressed out about X,Y and Z.

**R:** Yes I mean they come here...first of all you are giving all that information, other professionals' information and in addition you must give all your stuff.

**T3:** Exactly.

**R:** So it is all that emotional stuff. They are sitting here crying and then you are giving all that information and your information and they go home and think; *what?*

**T3:** Yea.

**R:** Do they remember a single thing is the question...

**T3:** Yea.

**R:** ...and that's where when I think how we did it now, was actually very beneficial for them, you know I mean even though they weren't as emotional now. I think what also came out from the two other case studies was that, this type of thing might have different outcomes at different stages like for example this might have been very beneficial for them in the beginning and the further you go along, it will maybe just be used quickly to review something and then put it away.

**T3:** Yes, but I feel that the clients need to be trained about this thing, this is actually a discipline that needs to be trained, they've got to become disciplined in doing their home programmes and I think that if they start at the early stage with these things and they are literally trained in the discipline of doing it then as time goes by and they start improving and spontaneous recovery happens then there won't be any difficulties or problems, then we won't have to do it this often, you won't have to do it every week, then you can do it sporadically over two weeks or three weeks.

**R:** That is interesting that you say that, that makes a lot of sense. Then the other question was what other factors do you think might have affected the effectiveness of the three strategies? You said already the mobile phone was obviously a problem. Do you think there is anything else that might have affected the effectiveness? I mean like we said they did have the motivation, they did have a lot of insight...

**T3:** Yes they did.

**R:** ... they were interested and it wasn't really that difficult for them to explain, I mean they knew...like you said it was appropriate for them.

**T3:** Yea it was quite appropriate for them...I don't feel there were many issues related to it...the only thing that I can think of now was just the fact that they weren't able to come here to us because often times we don't have the car here so we can't get into the car and drive around after clients so also accessibility wise, you know...

**R:** Yea today when she said she needs to put him in the chair and roll him here...

**T3:** Yes and it's far...down the hill, up the hill...I don't know how she does it.

**R:** I sat there and I was like; *what?*

**T3:** Yes, so I'm thinking to myself if I was that wife and I had my one day off for the week and I would have to think; should I take him to the hospital or not...I think caregiver motivation and caregiver's external responsibilities would also play a factor because I mean if you would weigh it up; should I go to town and buy us food or should I go take him to the rehab centre and let him do his exercises...when I think in terms of transportation, I think it is ridiculous. I think transportation and accessibility...that would stop many clients from not coming back, you know it would stop many clients from not carrying through or following through with their home-programme as well.

**R:** Which is maybe, now where you said that if we would use this package like the recording and the "please call me", the written information and the pictures... that you would then have to use that less because you give all this information and then you give them the chance to review and relearn and during a period of time manage themselves, that they won't actually have to come that much...

**T3:** Hm.

**R:** ...they would have to come more if you didn't give them anything...

**T3:** Yes.

**R:** ...and if you would use this package you would have to see them less...

**T3:** That's true.

**R:** ... which is also something that I didn't think of like that...

**T3:** Yes.

**R:** And then you said as an improvement or alteration of the combined strategies, you said video recording...why do you say so because it is more visual?

**T3:** Yes it is just more visual, he could see exactly how he made his lip in the session, or exactly how I made my tongue in the session or exactly how that maneuver went...to have that audio-visual because I know that most of the time I depend on how the client sees and senses. They have got to know, feel the placement in the mouth and they have got to actually see and feel and hear in the session and remember how it felt and you know all of that... but if we had a video of it then that would have also been another way of doing it...

**R:** Yes.

**T3:** ...but that would have then been if they had a TV or DVD or video...

**R:** Ok that makes sense and then you said use of normal cassette or CD that was obviously because you can't give everyone this thing...

**T3:** Yes.

**R:** ...and then you said so you have to look at what the client has. Oh and then you said recording on a mobile phone...that is so interesting because in the beginning I researched a lot of different technologies and this was one of the ideas that I presented to the focus groups and like you were saying if they have a good mobile phone, but most of the clients don't have...but it's a good idea I think...

**T3:** Yes because here I often find that a lot of our uneducated clients prioritise their money in a very funny way...they would wear the worst shoes but then they have got the best mobile phone...I think it's an image thing but I see that many of these clients have good mobile phones and I've had a client now recently; the little boy was very quiet in the session and I was struggling to build rapport with him and the mother took her mobile phone and she took a video of him at home on a mobile phone so I thought to myself ok well that could be a good way of actually doing it as well...if the client had the means.

**R:** Definitely you have got a good point there. Ok and then you said as a complete alternative you didn't give anything because [not audible].

**T3:** Yes we already discussed those ones before.

**R:** And then you said you strongly disagree that you had a negative experience because there wasn't really any...

**T3:** Yea there weren't any major risks involved so it was fine.

**R:** Ok and then you said following the completion of the study you feel like you would routinely use the combined or a part of these strategies and then you said...so would you use a CD or cassette if they had a player?

**T3:** Yes I would definitely use the strategy if I had something set up here at the centre and say for instance they gave me this in a budget and they gave me the resources to be able to do it, then I would have done it.

**R:** Ok, that's interesting. You are the first one that is saying that.

**T3:** Oh is it?

**R:** Yea the others liked the "please call me" and the follow-up most because you need some equipment even though the whole process is very quick. You use a digital recorder with USB, stick

it in the laptop burn that file onto the CD and it is a normal audio CD. The process is easy it is just the equipment that is difficult to get hold of, so again...

**T3:** Yes.

**R:** ...the idea is nice but the practicalities...

**T3:** The practicality of it yes that's why I'm saying if I had the budget and the equipment I would have done it and then I would have maybe set up the room in a different way and had a built-in recording or something like that, then it is not intrusive to the client. I would tell them, I'm going to record our session and then I just press play on my system and then we have our thing and then I just give the tape to them afterwards. Instead of having a whole thing on your table set up, which is quite intimidating to the client.

**R:** Yea that makes sense. And you also said the "please call me" for the whole of [the rehabilitation centre] for other therapists also.

**T3:** Yes instead of having a call me to my personal mobile phone because obviously I don't use my mobile phone for work purposes and I never give it to my clients. I feel that it would be more appropriate then to have the call me connected either to the hospital or connected to the rehab centre because I'm working in a team setup.

**R:** You see this is where I think the DFAQ system that was developed at UCT by the IT people there would be helpful. It is a site working through internet so you have the computer there and people can send SMSes like the MXit type thing for like one cent or whatever. You send a whole message to this site, a message pops up and then you can write them back and it's for free. You could put that into any clinic, clients know that they get a response if they have a problem. It is there, it is cheap, it is not invasive into the therapist's private lives. For rehab...

**T3:** I think for us it would be a really good idea because sometimes I feel with the clients...sometimes I will be able to help them or if I'm not available then at least if the "please call me" comes through to the centre, someone will always be at the centre, so even if I'm not there, one of the physios or one of the OTs can just sort the client out, then I don't have to feel burdened that the client isn't sorted out when I'm not here at the clinic. So I think it would be good to actually have that and also what if they have got a problem with their breathing and they need chest physio and something else happens and they need the occupational therapist, then we could have the team intervene.

**R:** Yes definitely, and you said that the combined strategies were useful for people who reside in impoverished areas...

**T3:** Hm.

**R:** ...is that because these things are sort of accessible to most of the people.

**T3:** Yes.

**R:** And then for low [health] literacy skills... is that because they can listen to something?

**T3:** Yes because they can listen instead of reading.

**R:** Yea and then the last one was not applicable because they were Afrikaans.

**T3:** Hm.

**R:** Do you have any other or additional comments that you would like to make?

**T3:** Any other comments... I don't have any comments right now.

**R:** Ok, thank you.

University of Cape Town

## **Appendix Q: Transcript of Interviews conducted in Case Study # Four.**

**R** = Researcher

**P4** = Client

... means there was a pause or an omission of irrelevant chat/conversation.

**R:** Ok, my eerste vraag is...het mevrou gevoel dat mevrou graag na die tape wou geluister het wat ons gegee het?

**P4:** Ja.

**R:** Ok en hoeveel keer het mevrou daarna geluister?

**P4:** Ek speel dit baie...

**R:** Is dit?

**P4:** Ja, as ek so alleen in die huis is dan speel ek.

**R:** Is dit? En hoekom speel mevrou dit so baie om...?

**P4:** Net om te luister nou en my gedagte af te hou van iets, dan sit ek maar net so.

**R:** Ok en toe mevrou van hier af weg gegaan het die eerste keer, was daar enige iets wat mevrou nie mooi verstaan het nie of wat mevrou nie mooi kon onthou nie?

**P4:** Nee ek het alles verstaan mooi ja.

**R:** Ok en dink mevrou dat die tape vir mevrou gehelp het om die informasie te volg?

**P4:** Ja, ja.

**R:** Is dit? Want mevrou het mos die geskryfde informasie gekry...

**P4:** Ja gekry.

**R:** ...maar wat het die tape nog daar by gesit?

**P4:** Ja, jy weet ek het nou al die informasie op 'n papier gekry, maar dit is vir my baie beter om die tape aan te sit en te luister ja.

**R:** Is dit? Is dit omdat daar nog ekstra informasie...

**P4:** Ekstra iets ja, ja. Die ekstra informasie wat daar nog by is ja.

**R:** Ok en is dit miskien ook omdat dit 'n stem was waarna mevrou ...

**P4:** Geluister ja, ja.

**R:** Ok, dit was meer persoonlik?

**P4:** Persoonlik ja.

**R:** Ok, en mevrou het mos gesê mevrou het baie daarna geluister. Het dit gehelp saam met wat [the speech therapist] gegee het...

**P4:** Ja is waar...

**R:** Het dit gehelp om deur die lang tyd altyd weer mevrou se stem te 'manage'?

**P4:** Ja.

**R:** So dit was nie net een keer nie...?

**P4:** Net een keer nie hu uh.

**R:** ...dit het gehelp met...

**P4:** Ja, ja.

**R:** Ok het iemand anders ook na die tape geluister?

**P4:** Ek het iemand gehad daar maar sy het nie lank gesit nie want toe gaan sy weer huis toe. Maar sy het gesê sy gaan weer kom luister.

**R:** Is dit?

**P4:** Ja.

**R:** En wie was dit? Was dit mevrou se buurvrou?

**P4:** Ja.

**R:** Is dit?

**P4:** Ja.

**R:** En het mevrou probeer om bietjie vir haar te verduidelik?

**P4:** Ek het haar verduidelik.

**R:** Is dit? En het die tape bietjie gehelp daarmee met die verduidelik of...?

**P4:** Sy het nou geluister bietjie maar toe seker nie vêr geluister nie want toe moet sy nou gaan, maar ek het die papier wat sy [the speech therapist] vir my gegee het, het ek vir hulle gewys en hulle sê dit is baie mooi ek moet dit net maar volg maar net. Maar so vêr, ek volg daardie en ek doen my oefeninge en so.

**R:** Ja ek kon mos ook onthou dat op die tape was mos ook die...die 'exercises' was mos op die papier, maar op die tape het julle mos deur gegaan deur die 'exercises'...

**P4:** Gegaan ja.

**R:** ...het dit ook net bietjie gehelp om vir mevrou weer te herinner hoe spesifiek...

**P4:** Spesifiek ja.

**R:** ... mevrou dit moet doen, dat mevrou nie iets verkeerd doen nie of...?

**P4:** Yes.

**R:** Dink mevrou dat ons vir ander mense ook so 'n tape moet gee as hulle huis toe gaan? Nie mevrou se nie maar 'n tape wat hulle...

**P4:** Ja, jy kan vir die mense wat nou almal met keel en sulke kwale het so 'n tape te gee want hulle kan luister daaran, en dit sal hulle verbeter, dan kan hulle mos nou luister waarom gaan dit...wat keel is nou...jy sien?

**R:** So dit sal vir hulle ook net help om die hele informasie te kry...

**P4:** Informasie te kry ja.

**R:** Ok en is dit miskien ook goed vir mense wat nou nie so mooi kan lees nie...

**P4:** Lees en skryf nou nie sien dat hulle net kan luister na die tape. Ons het baie mense vandag wat nie kan lees nie, jy sien. Dan praat jy met hulle maar hulle weet nie waar gaan dit oor nie.

**R:** Ja ok, en dan was daar mos die...ek het mos vir mevrou die nommer gegee van [the speech therapist] en die "please call me"...

**P4:** Ja.

**R:** ...was daar enige tyd waar mevrou gevoel het dat mevrou graag 'n "please call me" wou gestuur het?

**P4:** Nee niks nie, ek was 'alright' gewees met die.

**R:** Is dit, was daar nie enige probleme nie?

**P4:** Niks probleme gewees nie.

**R:** Ok maar hoe het dit vir mevrou gevoel dat mevrou geweet het; ok ek het die nommer, as ek 'n problem het, dan kan ek...

**P4:** Bel...ek het baie bly gevoel toe julle vir my die nommer gegee het so as enige iets nou kom met my stem dat ek kan bel. Ek het dit werk toe gevat. Ek het dit vir my baas gegee en sy het dit vir haar ook weg gesit toe sê ek; as ek enige iets nou weer oorkom, dan moet hulle sommer bel en sy was baie bly daarvoor gewees...

**R:** Ok bedoel mevrou as mevrou iets met die stem oorkom of...

**P4:** Ja, met die stem want baie keer as ek by die werk is dan slat my stem so toe...dan stuur hulle vir my dokter toe en hulle sit vir my aan suurstof en die...

**R:** Ok dink mevrou dit is 'n goeie ding om vir ander mense ook te gee die "please call me" en die nommer...

**P4:** Ja.

**R:** Hoekom dink mevrou so?

**P4:** Jy weet baie mense...ek weet nou nie hoe hulle voel nie maar soos ek voel, dit is die beste...gee vir hulle...want met die keel kan jy nie speel nie...soos die dokter ook sê, dit is baie gevaarlik.

**R:** En dit is ook kosteloos om n "please call me" te stuur so as n mens nie die geld het nie nou dadelik...

**P4:** Ja dan kan hulle mos nou net bel en se nou net...

**R:** Ok en die laaste is...hoe was mevrou se hele onderfinding met die 'service' wat...

**P4:** Wat julle gegee het...Ek was bly gewees. Ek het nie eers verstaan nie hoekom ek van die dokter af en dan na julle moet kom nie om nou daaroor gesels oor my keel nie, maar later toe voel ek nou meer...nee dit is n goeie iets...Want van dat julle met my gesels het, het ek huis toe gegaan en ek het gesit in my kamer en ek het die papiere so gevat en geluister en ek het gedink...dit is n goeie iets en ek het selfs my...as ek by die werk uitkom dan gaan ek in my kamer eerste, dan begin ek om my oeffeninge te doen en by die werk ook dan doen ek my oeffeninge daar, ja so ek is bly daaroor dat julle my gehelp het.

**R:** Ok ja dit is miskien ook omdat die dokter het al die mediese goed...

**P4:** Ja.

**R:** ...maar ons praat mos oor die stem, hoe om dit mooi te hou en...

**P4:** Ja maar ek het eers nou nie verstaan waaroor gaan dit nou net nie, maar nou verstaan ek, ek kan vir ander mense ook se waaroor gaan dit.

**R:** En dit is seker dan ook mooi as mevrou die tape het en die geskryfde informasie want dan kan mevrou vir hulle wys; dit is wat hulle gee...so gaan die oeffeninge...

**P4:** Ja want ek het nou al vir die mense gesê ek het mos nou n stem en daar is nou fout met my stem maar dit is nie se dat ek sal kanker kry nie, dit is die Here se wil en as die Here nou se dit is so dat ek kanker kry dan kan ek niks daaraan doen nie, maar julle help my nog altyd om my stem reg te kry.

**R:** Hm.

**R** = **Researcher**

**T4** = **Therapist**

... means there was a pause or an omission of irrelevant chat/conversation.

**R:** Ok so the first question was all of these here where it goes; I felt that the combination of these strategies were impractical or practical, you didn't tick anything here...

**T4:** Oh sorry I just thought you had to do one...

**R:** Ok but you can say, do you think...

**T4:** Ok, I thought it was a little bit impractical, well for that client it was fine because she had a CD-player at home and whatever but for the majority of the clients on the plateau land they actually don't so that could be a problem, a barrier I suppose before...

**R:** Ok.

**T4:** It's definitely not a waste of time if all clients had CD-players it would be great. A lot of clients also prefer listening to something constantly or seeing like a DVD of something that they have to do and I find they probably would be more motivated as well if I could assure that they all had CD-players at home.

**R:** Ok and then you said...

**T4:** In this client I thought it was unnecessary because she had written feedback as well and she could read so for her I thought it was unnecessary, for lots of other clients it could be very necessary because they just don't recall everything so I think on the whole it is quite a practical essential that could be implemented in the public health service.

**R:** Ok do you think it was still unnecessary even though she said it was quite a nice to have the exercises...?

**T4:** Yea but obviously I didn't know that now before, I heard her saying it during it and then I was like; oh ok that is going to be a nice conflict of interest for you to write about in your discussion [laughs]. So I obviously didn't know that.

**R:** Ok and then culturally appropriate or inappropriate...

**T4:** I thought it was appropriate.

**R:** Ok and then user-friendly/not user-friendly?

**T4:** Depends on if they have a CD-player at home. That was really the biggest barrier I think.

**R:** And oh yes and with the mobile phone, the same thing, it depends on if they have a mobile phone...

**T4:** Ja.

**R:** ... so you must always think of both things...

**T4:** Hm.

**R:** Ok, then ineffectual/effective in assuring continued contact and service delivery?

**T4:** It is effective in assuring continued contact, I'm just not a big stickler for that continued contact...

**R:** Like you said here at the bottom because...

**T4:** Yea after hours I don't like being contacted, I'm not a big person for working shifts either I leave my work at work. So that's me personally...ja I think it was just a little bit too close for comfort knowing that they have my mobile phone number because there are clients who when they do have your mobile phone number they really bug you, so that was a bit...

**R:** Oh do they?

**T4:** ...yea they do. She wasn't one but I think [the other speech therapist] might have had one that actually called her at strange times, so I wouldn't really give my mobile phone number out to most people. Maybe an e-mail address...that could work, if we lived in that kind of world.

**R:** Yes. You know it was actually...one of the other therapists was saying the same thing...they all have the problem with the personal space and then she said it would actually be much better if you had a computer at work where the "please call me's" get sent there and then the client's profile will pop up and you will know this client has a problem. You can phone from there because it stays at work, people then come in the morning and then see; oh there are three people, let me quickly phone them.

**T4:** Yea it could work, but we work for government and as you can see we do not all have ... in our offices, but it could be more useful definitely.

**R:** Yes ok great. Then suitable/unsuitable for information review by other health professionals?

**T4:** Yea it's suitable, it's fine, no problem.

**R:** You think so? Even though it's a recording? I mean you did give written information...but do you think the recording will maybe be a problem...for them to listen to?

**T4:** Other health professionals...I think a DVD or a video would be better...I mean I'm also thinking here in terms of student contact...it would be a lot better for them to see what's happening.

**R:** That's interesting ja ok...and then suitable/unsuitable for review by other family members?

**T4:** Same story.

**R:** Yea so it's suitable because...

**T4:** Yea I think it is...

**R:** ...they can listen...they can read...?

**T4:** Yea and most people can learn something I mean before I went to University I knew nothing about voice so I think it is probably good information for anyone to take a listen to so ja, I think so.

**R:** Ok, then effective/ineffectual in inducing compliance or behavioural change?

**T4:** It probably is effective...I would think that it would make sense, and I don't know what this client said in her answers but I suppose that she will give a better idea of the answer to that question.

**R:** Ok then the last one, generally ineffectual/effective in improving health literacy and recall thus decreasing/increasing efficacy of treatment?

**T4:** Hm it probably will improve if they had a CD-player at home, I mean obviously you are obtaining a lot of information at the same time and a lot of people just can't process and remember absolutely everything that gets told in one session...so I would say that it probably is effective...

**R:** Ok because...?

**T4:** They can also listen and just kind of track what they are doing and what they are not doing that they have to start doing...

**R:** So it's just an extra tool, is that what you are saying?

**T4:** Ja probably.

**R:** Ok great. Then you said you are undecided about if the strategies made a difference in the success in the client's treatment...

**T4:** Of this specific client I'm not exactly sure because she could read, there was someone around at home that could also read if she needed to, she seemed to understand what she needed to do so I'm not sure if the audio-recording...she didn't call or send an SMS or anything...but I'm not sure if the audio-recording made a difference as in if she didn't have it, I'm not sure if she would have done worse or better. So I'm undecided on that one.

**R:** Ok no problem and then you said you are also undecided about if she was more confident in managing her own health when she could get in contact and she could review the information... basically...

**T4:** I think that is what you are going to get from her, you are going to get that kind of information from the client.

**R:** And as you said before...

**T4:** Because I also always write a telephone number and I always invite them to give me a call if they notice any change in the voice and if they have any questions whatsoever about anything. I can always make contact with other professionals, so because I usually do that, I'm not sure if giving the mobile phone number additionally was of any benefit or not...

**R:** Ok, I mean the reason why I decided on the mobile phone number was just for people who don't have landlines and they don't have the money...

**T4:** Yea sure.

**R:** ...just like as a free alternative...

**T4:** Most people have mobile phones or know someone with one.

**R:** Ja so that was the only reason but basically this answer is the same as here...

**T4:** Hm.

**R:** ...because you gave her the...she didn't phone and you gave her the recommendations so basically you think...

**T4:** I'm not sure.

**R:** ...you are not sure, you can't really say which one it actually was which makes sense. Then you said that you felt that when she had left that the information that she was taking with her was clear and accurate and ready for review...

**T4:** Hm.

**R:** ...and then you didn't tick anything here where you said...

**T4:** I didn't because it says I do not feel that the combination is appropriate and I can't say that I don't feel that it is appropriate because I do feel it could be appropriate so...

**R:** For any of these is it?

**T4:** Ja I'm sure it could be, for all of them because at [the hospital] it's one of these institutions where you see a typical client [not audible], no matter what it's for, it's your typical client you see. We see platte land clients and west coast clients mostly and they all are fairly stereotypical, to a great extent they are so I don't think it makes a difference, what particularly they are here for.

**R:** And if you say stereotypical, do you also mean where they come from, literacy levels...

**T4:** Kind of typical backgrounds, socioeconomic status won't differ too much across the board...most of our clients where they come from and even education levels to an extent.

**R:** So you think this would be something that you could in this institution...?

**T4:** If they had a CD-player I would definitely but I would probably give them prerecorded one's ...instead of recording it in the session, pre-recorded information and just give them a CD as part of...

**R:** Do you think that would maybe become a problem if you had to do something more specific?

**T4:** Well you are obviously not going to have one general voice one but it would have to depend on pathology, like I mean vocal hygiene, it is going to be the same across the board, if it was going to

be [not audible] of the vocal cords where you give adduction exercises, if it is something else, social problems or whatever, I would give them numbers to call or whatever.

**R:** That is a good idea, and that would work for voice...

**T4:** It would work for voice because it is fairly specific with what you are going to do. I have to look at the ENT diagnosis and I know exactly what I am going to tell the client, so it could work for voice.

**R:** Yes because for the others...the pre-recorded would definitely then work for voice, for the others it would maybe be...

**T4:** Hm and probably laryngectomy as well, cleft palate maybe, dysphagia I don't know.

**R:** Because it always changes...

**T4:** It is just so broad.

**R:** That's a good idea, it's very interesting. Then you said as a complete alternative you didn't give anything...

**T4:** I couldn't think of anything else...once again you are going to have the technological obstacles and what clients have so other than that I couldn't think of anything else that we are not doing anyway, or that you brought up.

**R:** Ok no problem. And then you said you disagree that you had a negative experience...

**T4:** Yea I didn't think it was a particularly negative experience and I only now heard her response to the questions so I'm really glad it worked out for her.

**R:** Ok and then you said that you think the audio-recording was useful with specific clients...

**T4:** Yea it's only lack of resources, other than that I can't think of any reason why it could not be more effective...

**R:** And the "please call me", you said you liked the idea but not that it's coming to your mobile phone.

**T4:** Hm, but you are also going to find, we have a message book system, where if the client has a query they leave their name and number and we call them back within a day. It works really well.

**R:** Yes, I mean how nice would it be if you could have a system where it would come up on the secretary's computer the "please call me"...

**T4:** Yea sure.

**R:** ...and she would write it down...

**T4:** Yea it would be more convenient.

**R:** And then you said that they are good for people who reside in impoverished areas, because...it's free and...

**T4:** It is also ja they are just too far away to come and pop in if there is anything wrong so they have got a constant source of contact but also with the audio-recording, a lot of those clients don't always have access to telephones readily. Many times we would have to take the farmer's number, so then they have something to just fall back on...because all the information is on CD already.

**R:** Ok and then especially for people with low [health] literacy...and then you said...

**T4:** Yea I didn't think it was that useful with language skills because then the best would obviously be to get an interpreter.

**R:** Yea this question is actually not applicable because it was done in Afrikaans and so there weren't any problems.

**T4:** Yea and if I pre-recorded CDs I would record them in all the different languages...

**R:** Exactly...and then for other suggestions you said, paper based pamphlets with more pictures...

**T4:** Yea because often for the low education and literacy levels, we often find that if there are more pictures on they often just understand a bit better and they are more willing to read because it is not so much words so its not as intimidating...

**R:** Yes, because I've also found that a lot of clients will say; yes I can read fine... but it is difficult for them to process...

**T4:** Hm and they just look and they just see words and they go; no I'm not reading this it is too difficult. So it is a factor. I find less words, more pictures, more space makes them more willing to give it a try.

**R:** Yes and I mean I must say the handouts that you gave her were actually so nice because it was just one sentence, big print.

**T4:** Hm and also quite big because a lot of our clients are often older and have visual impairments.

**R:** Yea, it's easier to manage and read through and process, definitely.

**T4:** Hm.

**R:** Do you have any other comments, anything else you can think of?

**T4:** Hm just that I really, I would be a great way to implement...more resources for clients to take home. We do try and offer even though we are a state hospital the best kind of treatment we can with what we have and I think it would be a great initiative if it was funded.

**R:** Yea that's great. It is probably also just you know the feeling that I have been getting from the others is that it's just to equip them...

**T4:** Ja, definitely.

**R:** ...with something that they can take home, I mean you are already giving her a handout which is already good...

**T4:** Hm

**R:** ...but a lot of therapists don't often give anything...

**T4:** Hm but it also depends on what your motivation is for the clients and also realising the population that you are working with where they will use their last money because they are concerned about their health...so you can't come and waste their time. You need to give as much as you can especially for the people who live far so at least from my part I try and do as much as I can for the client while they are here. They need to leave feeling that it was worth that 60R or whatever that they gave out.

**R:** Yes so basically the idea you think is great, the audio-recording is great, "please call me" is great...

**T4:** I do.

**R:** ...the only thing that is a problem is that it's not readily available yet. It is not something that can just happen easily...

**T4:** Hm.

**R:** ...you would have to put a little bit of money in it first...

**T4:** Yea it would be funding.

**R:** Ok that makes sense, I know that.

**T4:** What did you find with this study? Did you find that you achieved what you thought you would, or you wanted to or the outcomes that you expected or projected?

**R:** You know the nice thing is that I didn't go into this study wanting to say yes or no...I went into this study to explore.

**T4:** Ok so you weren't too bothered about what the answer was.

**R:** Hm and what I found is that basically like you said, the idea is good even for people that can read sort of but at the moment it is still a bit of a problem because of the tools that aren't so readily available.

**T4:** Yea, the reason why I also give written handouts and quite a bit of information on anatomy and physiology is also just to improve efficacy where the clients know why they need to do the therapy.

**R:** Yes so that's the thing that I got, give them as much as you can, as many tools as you can and if they have a problem they can go back to the information...

**T4:** Hm.

**R:** ...and another thing that I found is that you can do all of this, it's a good idea and a good initiative but in the end it still depends on the client.

**T4:** Oh definitely, they can decide to chuck the recording but what I also think could be interesting for you is to perhaps try it at the clinics rather than at hospitals because all the therapists here are trained at University to respond to the client on the level that they are. So I'm not going to make any complicated text to give to the client, I'm going to do it in lay language.

**R:** Yea another thing that I found is that you can do all of this, you can stand on your head...

**T4:** Yea some clients comply and some don't ...it depends a lot on their motivation.

**R:** Definitely.

**T4:** Obviously this client has had the motivation because she has seen four members of her family dead in the past few years, it is tragic and terrible especially because one died of throat cancer which she could also possibly pick up.

**R:** Yea and it was the same with the other participants that I saw...they stayed in a shack but they were so enthusiastic...

**T4:** Yea definitely.

**R:** ...and they were also...give them the tools, equip them even though in the end it still depends on them... I think non-compliance would happen less if they feel like; oh look we got a CD, this is something new...

**T4:** And look what I got at a state hospital...because they always expect the least from state hospitals. The problem that I still found with this client was that she still followed the medical model where the doctor said this, the doctor said that, we mustn't ask questions, we must just go with it. So they often come here and they say I don't know why the doctor sent me and I have to explain my and everyone else's roles in the team because they didn't get that. They think you are like the old medical model, you see one person, you do what they say, you don't ask questions. So with that kind of client something like a CD is useful because it just answers a lot more of those questions, it reminds them why they had to do certain things. It is especially useful for someone who is going to be intimidated in a hospital setting like this to ask questions. Especially with the plateau clients who are not used to this.

**R:** So maybe the "please call me" will be used less because they are scared?

**T4:** No they probably won't but if they can listen to the information again it could help or they could have listened to it enough times to come and ask questions next time.

**R:** But you know what I've also found was that sometimes they will listen to it but they don't have enough insight to realise...

**T4:** I think you'll be surprised because often those that will feel intimidated will bring someone with them and this person is the cleverest that they know so *they* have to liaise...so often you end up

talking to the person who they brought with, who will assist them at home. If they don't I try and make contact with the family or write a letter for them to explain.

**R:** Yea but I mean now with the "please call me"...you know if they sit at home...it's fine you gave them all the information...they can review, they can read, they can listen but then if something doesn't work out for them...will they actually realise that and send a "please call me" to get into contact and get help?

**T4:** Hm. What else you find in most of the communities where our clients live...they will go to the one person in the road who they think knows everything to get help. They will rarely phone the therapist again because firstly they think you work in a big hospital and you are too busy and secondly it is cheaper to just see the aunty down the road, it's that strong cultural influence still...but you try and make a connection in the session with the clients so that it's not a problem if they phone you.

**R:** Hm and do you think it's also because they are just not used to it...say now in a few years time this whole "please call me" thing takes off and clients know about this system, it's not just hypothetical...

**T4:** Hm I also find that often when clients phone they will ask someone else to call on their behalf if they...you know?

**R:** Ok.

**T4:** I think you need to understand the population you are working with because then all the cultural influences will influence the therapy and even contacting people and so on. I think there is a very strong cultural influence that influences treatment with clients...especially on the platte land where speech therapy is not a main concern...other conditions like hearing loss and high blood pressure for example are. So if the speech thing is not working it's like; oh well we tried, too bad. They just accept their disorder and people go on.

**R:** Yea.

**T4:** Even though with the advent of more advanced technology, I still find platte land is platte land and that is how things have always been done and to a great extent that is how they always want it to be. It's not that they don't always know how to use technology but they are not always interested.

## Appendix R: Table 8. Strategies and their advantages/disadvantages in intervention

Strategy	Advantages	Disadvantages
<i>Written materials</i>	<ul style="list-style-type: none"> <li>○ Allows recall and revision of important clinical information and recommendations outside of stressful clinical environment.</li> <li>○ Easy to file, store and copy.</li> <li>○ Appropriate for speedy review and reference.</li> </ul>	<ul style="list-style-type: none"> <li>○ They are only of advantage to people who have good literacy skills.</li> </ul>
<i>Detailed explanations, demonstrations and practice during sessions</i>	<ul style="list-style-type: none"> <li>○ Make it easier for clients with low health literacy skills to understand, process and organise health information.</li> </ul>	<ul style="list-style-type: none"> <li>○ Only applies to the period of time that the client spends with the health professional.</li> <li>○ No access to these advantages post-consultation.</li> <li>○ High level of insight is needed.</li> </ul>
<i>Repetition or revision of clinical information during sessions</i>	<ul style="list-style-type: none"> <li>○ Aka the “teach-back” technique helps to reinforce information that needs to be understood and recalled.</li> </ul>	<ul style="list-style-type: none"> <li>○ Only applies to the period of time that the client spends with the health professional.</li> <li>○ No access to these advantages post-consultation.</li> <li>○ High level of insight is needed.</li> </ul>
<i>Illustrations</i>	<ul style="list-style-type: none"> <li>○ Illustrations serve as an additional medium to put information across.</li> <li>○ They make it potentially easier for clients to understand, process and organise health information.</li> <li>○ Is of most assistance to clients with low literacy skills.</li> </ul>	<ul style="list-style-type: none"> <li>○ Need for educational effectiveness, cultural appropriacy, additional time and human resource to teach meaning of illustrations.</li> <li>○ Need of appropriate visual literacy skills.</li> <li>○ Some information is often too abstract and multi-faceted to readily depict in illustrations.</li> </ul>
<i>Support from family member or significant other person and SLP during and after consultation</i>	<ul style="list-style-type: none"> <li>○ This person can deal with information more objectively.</li> <li>○ They do not have psychological and physical interferences distracting them during consultations.</li> <li>○ Can serve as an independent information resource and provider of support to a client.</li> <li>○ Benefits of support (e.g. reassurance, comfort).</li> </ul>	<ul style="list-style-type: none"> <li>○ A second person might not always be readily available.</li> <li>○ Involves additional costs for travel.</li> <li>○ Regular contact between health professional and client is not always a reality.</li> </ul>

<p><b><i>Telephonic contact</i></b></p>	<ul style="list-style-type: none"> <li>○ Medium for reassurance, problem-solving, clarifying clinical information and providing support post-consultation away from the stressful clinical environment.</li> <li>○ Best at times of crisis.</li> <li>○ Ensures follow-up and the possibility of regular contact between client and SLP.</li> <li>○ Eases clients' anxieties by knowing they can get into contact with their SLP.</li> <li>○ Useful for reminder calls.</li> <li>○ Builds a relationship between SLP and client.</li> </ul>	<ul style="list-style-type: none"> <li>○ Clients that stay in rural areas may not have a telephone of their own.</li> <li>○ Some clients have mobile phones but no airtime.</li> <li>○ Clients and their families seldom take advantage of being able to get into telephonic contact with the SLP for reasons that are unknown at this stage.</li> </ul>
<p><b><i>Choose fewer goals in therapy together with intensive short-term block therapy instead of long term therapy</i></b></p>	<ul style="list-style-type: none"> <li>○ Makes it easier for clients to understand and remember important clinical information, goals and procedures.</li> </ul>	<ul style="list-style-type: none"> <li>○ Clients need the financial means and time to attend frequent therapy.</li> </ul>
<p><b><i>Audio-visual materials</i></b></p>	<ul style="list-style-type: none"> <li>○ Visually puts information across and make it easier for clients to understand, process and organise health information.</li> <li>○ Use and response to multimedia is increasing constantly.</li> <li>○ Beneficial for clients with low or no literacy skills.</li> </ul>	<ul style="list-style-type: none"> <li>○ A variety of up-to-date, client/disorder specific multimedia materials for Speech-Language Pathology are not yet readily available in South Africa.</li> <li>○ Clients need appropriate visual literacy skills.</li> </ul>
<p><b><i>SMS</i></b></p>	<ul style="list-style-type: none"> <li>○ Currently 70% of people in South Africa have access to a mobile phone (Internet World Stats, 2007).</li> <li>○ Cellular networks cover 90% of the country.</li> <li>○ Is a medium popular with the younger generation.</li> <li>○ Best when recommendations are straightforward and can be provided in point-form.</li> <li>○ A tool for quick reminders.</li> <li>○ By using the "please call me" function, clients can get into telephonic contact with the SLP at no cost.</li> <li>○ Clients can do this out of the privacy, safety and comfort of their own home. Caregivers would not need to leave the patient unaccompanied.</li> <li>○ No need to find the nearest public phone.</li> </ul>	<ul style="list-style-type: none"> <li>○ Clients need to have good literacy skills and be familiar with the technology.</li> <li>○ Might not be readily used by older clients who have not been exposed to this form of communication.</li> <li>○ Need for good dexterity.</li> <li>○ Not ideal for possible life-threatening situations as there is too much room for misunderstandings.</li> <li>○ Too restrictive (often too much information that needs to be conveyed).</li> <li>○ Can be tedious and time-consuming.</li> <li>○ Cannot provide practical demonstrations or immediate feedback.</li> </ul>

<p><b><i>Reminders on mobile phones</i></b></p>	<ul style="list-style-type: none"> <li>○ Serves best as a post-consultation reminder of important points.</li> <li>○ People carry mobile phones with them at all times so reminders would be immediate.</li> </ul>	<ul style="list-style-type: none"> <li>○ Clients need the dexterity to make use of this function.</li> <li>○ Advice is not always clear-cut and straight-forward to put into point-form.</li> <li>○ Not all mobile phones have this function.</li> <li>○ Additional time is needed to type reminders into mobile phones.</li> <li>○ All mobile phones operate differently so SLPs need to get accustomed to them first.</li> </ul>
<p><b><i>Audio-recordings</i></b></p>	<ul style="list-style-type: none"> <li>○ Beneficial for clients with low or no literacy skills.</li> <li>○ CDs/cassettes are re-recordable and thus cost-effective.</li> <li>○ More durable than written information on paper.</li> <li>○ Clients can listen to the CD/cassette while they are attending to a client.</li> <li>○ Information can be reviewed outside of stressful clinical environment as often as wanted/needed.</li> <li>○ It can be recorded in clients' native language</li> <li>○ Is personalised and provides the comfort and reassurance of listening to a human voice (Tattersal et al., 1994).</li> <li>○ Spoken word has greater power to hold attention than the printed word (Santo et al., 2005).</li> <li>○ Time and healthcare costs are reduced if clients use this strategy to effectively manage their (their child's) disorder.</li> <li>○ Can share information directly with family and thus decrease the possibility of misunderstandings or forgotten details.</li> <li>○ Only adds minimally to the already unmanageable workload (Tattersal et al., 1994).</li> <li>○ Information is clear, accurate, complete and available for problem solving and discussion.</li> </ul>	<ul style="list-style-type: none"> <li>○ Some SLPs prefer personal contact as they are then more in control of what and how the client recalls and interprets the clinical information.</li> <li>○ Need for access to a CD/cassette player.</li> <li>○ Recording consultations may inhibit open discussions (Santo et al., 2005) (the chances of this happening can be reduced by actually just recording summaries at end of session).</li> <li>○ Cannot easily share information with other health professionals.</li> <li>○ Not be easy for health professionals to file, store, and copy or have available for speedy review and reference.</li> </ul>