

**THE MEDICAL AND REHABILITATIVE  
MANAGEMENT OF PERSONS WITH  
MOTOR NEURON DISEASE**

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**BY**

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## DECLARATION

I hereby declare that this research report is my own original work. Except for technical assistance as detailed in the Acknowledgements of this report, I am responsible for the text of this study and the conclusions reached.

No part of this report has been submitted for a degree at any other university.



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Date

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## ABSTRACT

Although the management of Motor Neuron Disease (MND) remains devoid of a cure, persons affected by this devastating condition are nonetheless entitled to the best quality care that is available. A paucity of information exists documenting the perceptions of healthcare consumers regarding the management that is provided. In addition optimal healthcare comprises an intricate interaction of patient-centred care, patient-centred communication, and bioethical practice, and when these three dimensions are implemented according to acceptable standards, high-quality healthcare is perceived by the healthcare consumer. Given however the socio-political challenges that face healthcare systems, the management of MND needs to be considered against current trends in service delivery and the need for evidence-based medicine. An exploratory study was therefore conducted to investigate the perceptions of persons with MND and their family members regarding current medical and rehabilitative management. The sample comprised six persons with MND who presented with a communication impairment, as well as six family members. Participants' perceptions were elicited through the use of a semi-structured interview schedule, and questions focused on healthcare professionals' behaviours during healthcare encounters. In addition emphasis was placed on the potential of the communication impairment to influence management. A standardised dysarthria assessment was conducted to characterise the nature of the speech impairment in each person with MND. Qualitative responses obtained from the interviews were analysed in accordance with a matrix-based approach, while quantitative data from the dysarthria assessment were analysed using descriptive statistics. Despite individual variability, perceptions of both persons with MND and their family members revealed general dissatisfaction with regard to medical and rehabilitative management. The majority of persons with MND were not referred for intervention following diagnosis, and the recommended team approach for the management of MND was absent. In addition the bioethical practice of many healthcare professionals was deemed questionable, and the communication impairment was perceived to impose a significant burden on the healthcare encounter. Furthermore all participants perceived a lack of available support systems for persons with MND, and it was thus not uncommon for individuals to pursue complementary and alternative medicine. South Africa's current healthcare climate also appeared to further limit healthcare for this clinical population. In an attempt to improve the management of MND, implications are provided in terms of health communication, intervention, bioethical practice, and support systems. A proposed new framework of ideal service delivery for healthcare consumers of MND management is also presented. Further implications are outlined with regard to the need for innovative models of service delivery in South Africa's healthcare context, as well as the role of speech-language pathologists, other healthcare professionals, policy makers, and educators in the improvement of the medical and rehabilitative management of MND. Finally theoretical implications and implications for future research are also documented.

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## **CHAPTER ONE**

### **INTRODUCTION**

*“On the day of diagnosis the whole world dropped and I thought ‘what now?’. There was just a black hole. Nobody tells you what is available out there and I felt so alone. They just don’t understand and they have no compassion. Why don’t they forget I am going to die and rather give me some hope?”*

(Participant in this Study)

#### **1.1 OVERVIEW OF THE STUDY**

For more than a century, traditional models of healthcare have viewed the diagnosis of Motor Neuron Disease (MND) as synonymous with a death sentence and anonymous to the idea of hope or the belief that any form of intervention can be of value to this patient population. Stemming from such an attitude of nihilism, Leigh et al. (2003) state that the management of MND has been evolving for the last 20 years such that whilst a cure remains unidentified, MND is now a treatable condition. It thus behoves professionals to assist patients in every way possible, facilitating the transition from active life to death in an as dignified, respected and compassionate manner as possible (Gelinas, 1997).

Current transformations in modern medicine mean that healthcare professionals (HCPs) must now respect patient autonomy and choice by relinquishing their power and authority, and recognising the patient’s point of view (Ahmedzai et al., 2004; Sullivan, 2003). The concept of patient-centred care has therefore become the crux of “good” medicine, where the social, psychological and biomedical needs of the healthcare consumer are acknowledged by a compassionate HCP in an empathetic environment that offers shared power and responsibility between the patient and the practitioner (Mead & Bower, 2000). In addition by acknowledging the patient’s point of view in healthcare decisions and respecting patient autonomy, the behaviour of HCPs is not only congruent with patient-centred care, but also more bioethical in nature and regarded as morally acceptable by healthcare consumers. For Sullivan (2003) this shift from objective to subjective healthcare falls within a bioethical framework of practice, and functions not to question the goals of objective medicine, but rather to improve the cost-effectiveness of medical care and the quality of life for all patients. Moreover on this basis, quality healthcare also requires that the complex

interactions transpiring between patients and professionals be grounded in successful communicative exchanges. As a result patient-centred communication is therefore a central component in patient-centred care, and contributes to satisfactory healthcare encounters, improved health outcomes, and compliance in healthcare management (Mead & Bower, 2002). However in light of the socio-political challenges inherent to the South African healthcare system (Ross & Deverell, 2004a) and the significant emphasis placed upon the need for evidence-based medicine, it is essential that HCPs are provided with the best available evidence regarding treatment options, which not only fit defined models of managed care but are also amendable to cost-saving strategies (Bensing, 2000). Thus in order to achieve high-quality healthcare the need arises to view service delivery from the perspective of patient-centred care, patient-centred communication, and bioethical practice, against the backdrop of current trends in clinical service delivery and the practicalities of scientific and measurably obtainable outcomes which are cost effective.

While the search to establish a cure for MND is of prime importance to most researchers, there is an ethical and professional responsibility for HCPs to provide the best quality care in the interim. Even if treatment is not “curative” it needs to be “life-prolonging” or patient-specific by providing amongst others, psychological, physical, social and spiritual support (Ahmedzai et al., 2004). The best possibility of achieving quality of life in MND therefore lies in team intervention, where the knowledge and skills of a variety of disciplines function in harmony to enhance well-being and meet the many needs of patients and their family members (Leigh et al., 2003). Furthermore the quality of the relationship that arises between healthcare consumers and HCPs is of prime importance, because the interactions between these two parties have a powerful influence on the outcomes of the individual’s health and his/her perceptions regarding the quality of healthcare that is received (Stewart, 1984). However in the presence of the communication impairment that is experienced by the majority of persons with MND, the potential for communicative breakdowns in the relationship between the healthcare consumer and the HCP is undeniable. Not only might a patient be unable to convey his/her specific concerns or preferences regarding the medical and rehabilitative management of MND, but also the professional may be unskilled in eliciting or revealing the patient’s point of view. Consequently the quality of patient-centred care and the overall satisfaction regarding the medical and

rehabilitative management of MND is thus questionable. Moreover despite the vast amount of literature which suggests that the best way of evaluating the quality and outcomes of service delivery is to elicit the perceptions of patients themselves (Charon, 2001; Stewart, 2001), by virtue of the communication impairment persons with MND may be hampered from revealing their perceptions regarding the medical and rehabilitative management that is rendered.

The present study therefore investigated the perceptions of persons with MND and the perceptions of their caregivers (i.e. family members, significant other individuals or individuals trained as carers) with regard to current medical and rehabilitative management practice for MND. It was anticipated that by understanding healthcare consumers' perceptions regarding the medical and rehabilitative management of MND, implications would arise for improving standards of healthcare and enhancing the overall quality of service delivery for this consumer-base. Since the management of neurodegenerative conditions has been viewed with scepticism in light of the impending death, improved healthcare for such clinical populations is well overdue. Furthermore in an era of advancements in all spheres of medicine, healthcare consumers have urged HCPs to minimise the devastating impact that MND has on an individual by reducing the resulting disruptions to quality of life and by acknowledging that until the bodily functions that sustain life cease, the person with MND is as deserving of quality healthcare as in the case of any other illness (Francis, Bach & DeLisa, 1999).

## **1.2 LITERATURE REVIEW**

At its scientific best, medicine will always be a social act where patients will rely on interactions with HCPs to accompany them through their illness (Elwyn & Gwyn, 1999). Despite remarkable advances that have been made in the diagnosis and treatment of disease, many HCPs reportedly lack the ability to recognise the plight of their patients, offer empathy to those who suffer, and assist individuals through their illness with honesty and courage. On this basis a scientifically competent medicine alone is insufficient to help patients make sense of living with a loss of health, and to attach meaning to suffering that is experienced (Charon, 2001; Kaba & Sooriakumaran, 2007). Patients, their families, and HCPs themselves have thus commented in the literature on the lack of compassion, empathy, and concern for the

psychosocial aspects that are believed to be inherent to any healthcare encounter (Jotkowitz & Clarfield, 2005). Consequently there is widespread encouragement for members of the medical community to renew their commitment to professionalism, where the uniqueness of patients, their individual needs and preferences, and their emotional status are placed at the forefront of all healthcare encounters (Charon, 2001; Jotkowitz & Clarfield, 2005). HCPs are therefore called to use the best sources science has to offer to their patients, without neglecting important psychosocial issues or the uniqueness of each patient as a person (Bensing, 2000). After all, *“It is as important to know the patient who has the disease, as it is to know the disease which the patient has”* (McCormick, 1996 as cited in Bensing, 2000:21).

Prior to the 1980s health and illness were conceptualised in terms of a biomedical model. The nature and cause of disease were associated with specific etiologies, and intervention was based on medical knowledge and skills. The HCP practised from a paternalistic framework where he/she had complete control over the healthcare encounter, and the patient was simply a passive recipient of any treatment provided. The focus of this approach was to therefore treat the disease of the patient’s body, rather than treating the person (Gilbert, Selikow & Walker, 2002). Contrary to this view of disease, Engel (1977 as cited in Borrell-Carrió, Suchman & Epstein, 2004) believed that because a biochemical alteration does not translate directly into illness, it must be the interaction of diverse causal factors including those at a molecular, individual and social level, that contribute to the experience of illness. As a result the only way to understand and respond to a patient’s suffering is to consider simultaneously the biological, psychological and social dimensions of illness. According to Borrell-Carrió et al. (2004) Engel’s biopsychosocial model was therefore an alternative to the biomedical model, which aimed not to condemn the significance of biomedical research but rather criticised the narrow thinking that lead HCPs to believe that patients were mere objects of study. Consequently Engel’s biopsychosocial model has gained momentum since the mid-20<sup>th</sup> century, and has been viewed by many as an ideal philosophy and a practical clinical guide that not only brings equality, empathy and compassion into medical practice, but also aims to avoid both the dehumanisation of medicine and disempowerment of patients (Borrell-Carrió et al., 2004).

Since the inception of the biopsychosocial model, the emphasis placed on empathy and compassion is believed to have transformed medical practice to a more superior level. However in view of the ever-changing and progressive nature of medicine, HCPs are challenged to question whether the principles and practice of the biopsychosocial model can be applied 25 years later without any change or reconsideration of how to achieve optimal healthcare delivery in the present context. Whilst Borrell-Carrió et al. (2004) suggest that the biopsychosocial model has been viewed by many as a shift towards “better” medicine, a closer look reveals that it is perhaps only a philosophy of clinical care that offers a way of looking at illness on multiple levels, and acknowledging on a superficial level the patient’s subjective experience as a contributor to diagnosis, health outcomes, and humane care. Alone the biopsychosocial model appears insufficient for eliciting and understanding in detail the patient’s full experience of illness (Kaba & Sooriakumaran, 2007), and is therefore also inadequate in terms of treatment because Charon (2001) posits that it is only once the patient’s personal meaning of illness is understood in-depth, that HCPs can begin to intervene effectively and alleviate suffering. As a result of the criticism surrounding the biopsychosocial model, a more patient oriented approach in the form of patient-centred care has therefore become a popular and closely associated concept with the biopsychosocial perspective (Kaba & Sooriakumaran, 2007). Within the realm of patient-centred care, HCPs are urged to attend to patients’ psychosocial and physical needs, convey a sense of partnership and positive regard to patients, and facilitate patients’ involvement in decision-making about their healthcare (Kaba & Sooriakumaran, 2007; Mead & Bower, 2000; Mead, Bower & Hann, 2002). In addition patients are also encouraged to communicate with their HCPs, speaking their mind and refusing to accept passively that which is rendered by any professional. Patient-centred care is thus a product of the many perceived limitations associated with conventional medical practice, and functions on the HCP’s ability to integrate the patient’s perceptions into the healthcare encounter (Mead & Bower, 2000; Mead et al., 2002). When such integration is achieved, outcomes pertaining to care are said to improve such that patients report greater satisfaction and reduced anxiety during healthcare encounters, as well as demonstrate greater adherence to treatment, improved symptom resolution, and enhanced psychological and functional well-being (Kinmonth, Woodcock, Griffin, Spiegel & Campbell, 1998).

Despite the concept of patient-centred care becoming increasingly popular and indicating a mark of quality healthcare, the term is not well understood beyond a superficial level and is most commonly acknowledged for what it is not – technology-centred, doctor-centred, or disease-centred (Stewart, 2001). Due to a lack of conceptual and methodological clarity in studying patient-centred care, the concept remains vague and conceptual and empirical developments have therefore been hampered (Mead & Bower, 2000; Mead et al., 2002). However given the widespread importance that the literature attributes to patient-centred care (Mead & Bower, 2000; Stewart, 2001), irrespective of its lack of specificity or exact definition, conceptual and methodological uncertainties should not prevent the study and development of this relatively new concept in medicine. Rather HCPs should perhaps make every attempt to broaden and consolidate their knowledge on the concept because understanding patient centeredness is fundamental to quality healthcare. Furthermore according to Stewart (2001), studies indicate that most patients desire patient-centred care and want HCPs to a) explore their concerns and needs for information, b) seek an integrated understanding of their world, their emotional needs, and their life issues, c) find common ground on their problems and agree mutually on management, d) enhance health promotion, and e) enhance the continuing relationship between themselves and their patients. And thus in view of these patient desires, HCPs are encouraged to engage in a patient-centred approach and implement it into the current healthcare arena.

According to Mead and Bower (2000), patient-centred care differs from biomedical practice on the basis of five key dimensions. Firstly in accordance with the “biopsychosocial” dimension, HCPs are called to broaden their perspective on illness and consider not only the biomedical variables of the patient but also the social, emotional and psychological factors that are inherent to the individual as well. In addition HCPs should also be open to the patient’s hidden requirements of the healthcare encounter that are not overtly displayed by the individual, and which may extend beyond his/her biomedical needs. Secondly the dimension of “patient-as-a-person” looks at understanding the individual’s experience of illness, considering each patient as an idiosyncratic personality within his/her own unique context. The dimension of “sharing power and responsibility” relates to greater patient involvement in the healthcare encounter, and promotes an egalitarian relationship whereby there is

symmetry in the power and control held between the patient and the HCP. The fourth dimension of “therapeutic alliance” focuses on the core attributes of empathy, congruence and unconditional positive regard to enhance the personal relationship between the patient and the HCP. By attending to the socio-emotional aspects of the healthcare encounter, the relationship between healthcare consumer and professional is optimised. The final dimension of “doctor-as-person” looks at the personal qualities of the doctor and his/her self-awareness regarding the manner in which medicine is practised. While the literature speaks specifically of the qualities of a doctor, it is possible that such attributes could apply to any HCP. According to Mead and Bower (2000) this final dimension therefore considers healthcare as a “two-person medicine”, whereby the patient and the HCP influence each other in the healthcare encounter and cannot be separated. On the basis of this conceptualisation it is evident that patient-centred care thus comprises multiple components, and embodies a complex set of professional, sociological and political ideals about the healthcare consumer-HCP relationship (Mead & Bower, 2002; Mead et al., 2002).

In view of Mead and Bower’s (2000) preceding definition of patient-centred care, it is clear that all five dimensions of this concept rely on successful communication between the patient and the HCP so as to achieve effective health outcomes. For example in order to acknowledge the psychological and socio-emotional factors relating to the patient, and to understand his/her unique view of illness, the HCP must be able to elicit these experiences through the appropriate communicative means. In addition, “two-person medicine” and an egalitarian relationship are dependent upon effective communication between the patient and the professional in order to achieve mutual agreements regarding various aspects of healthcare. A burgeoning of literature thus agrees that good communication is the cornerstone of a patient-centred consulting style and is fundamental to bringing the benefits of medical advances to patients (Boon & Stewart, 1998; Mead & Bower, 2002; Ruiz-Moral, Rodriguez, de Torres & de la Torre, 2006; Teutsch, 2003). The essence of delivering superior quality healthcare, building constructive healthcare consumer-HCP relationships, achieving desired health outcomes, and enhancing patient satisfaction is therefore founded upon sound health communication (Ammentorp, Sabroe, Kofoed & Mainz, 2007; Boon & Stewart, 1998; Teutsch, 2003). Since it is evident that the inter-relatedness of patient-centred care and communication is thus the foundation of high-

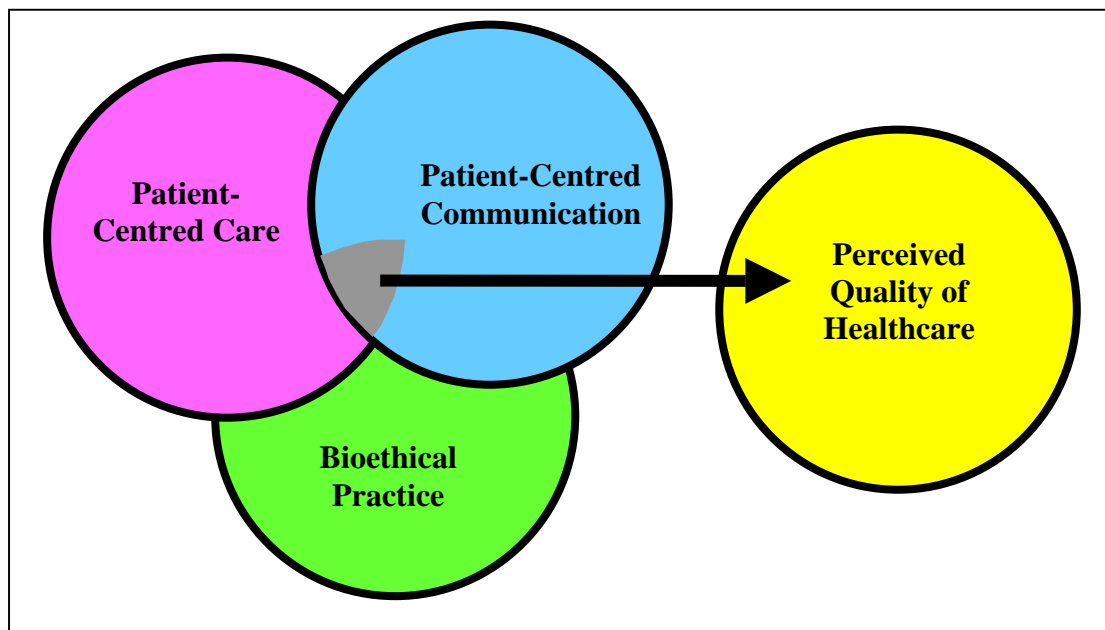


quality healthcare, the Committee on Quality of Health Care in America (2001 as cited in Epstein et al., 2005) recently endorsed patient-centred communication as a central component of quality clinical service delivery. The goal of patient-centred communication is to facilitate HCPs in providing care that is both concordant with the values, needs and preferences of patients, and also allows healthcare consumers to provide input and participate actively in their own healthcare. According to Epstein et al. (2005) an operational definition of patient-centred communication encompasses the following four domains; the patient's perspective, the psychosocial context, shared understanding, and shared power and responsibility. Said differently, in order to succeed with a patient-centred way of communicating, patients must be given the opportunity to express their thoughts, feelings, expectations, and opinions. Also, instead of labelling patients as an object with a disease, they should be treated as people with a problem and made to feel that they are understood by their HCPs (Fossum & Arborelius, 2004). By virtue of the components that characterise patient-centred care and patient-centred communication, it is clear that large overlap exists between these two concepts, and thus in order to achieve high-quality care where the patient as a person is perceived as the pinnacle of healthcare, effective communication on the part of both the healthcare consumer and the HCP is vital.

In acknowledging that patient-centred communication against a backdrop of patient-centred care results in high-quality care, the question arises as to what specifically constitutes quality healthcare. According to the literature, quality patient care is delivered through effective healthcare consumer-HCP communicative interactions, and comprises a modality for educating patients about their care, offering a human interface to disease, empowering patients to make appropriate decisions regarding their personal health, and demonstrating respect and empathy for the patient (Teutsch, 2003). By and large these characteristics of medical practice are expected by both patients and many HCPs alike, and in their simplest form are perceived as the "rightness" or "correctness" of patient care (Kubsch, Hankerson & Ghoorahoo, 2005). Questioning whether actions are morally right and adhering to obligations that one person owes to another (Loewenberg & Dolgoff, 1996), moves healthcare practice into the realm of ethics. In recent times ethics has become an important component of law, business, medicine and other professions (Keane, 1994). According to Beauchamp and Childress (1994) ethics is a generic term referring to the

understanding and examining of the moral life, or how relations between people allow them to live in peace and harmony. Medical ethics on the other hand examines the morality of medicine and asks what morality should be for physicians, for patients, for organisations, and for health policies (McCullough, Coverdale & Chervenak, 2004). Extending on from medical ethics and of relevance to this study, is the concept of bioethics or the value judgements pertaining to human conduct within a medical paradigm. Bioethics therefore not only includes medical ethics but also addresses what morality should be for all HCPs, patients, basic science, clinical research, and health policies (Beauchamp & Childress, 1994; McCullough et al., 2004). On the basis of sound implementation of bioethical practice, controversial and troubling issues that compromise healthcare can thus be resolved. Consequently when moral decisions regarding the maintenance of life and/or quality of life are made, the right of the patient to make decisions is acknowledged, the professional is perceived as truthful, loyal and beneficent, and access to treatment is available and fair. Moreover in such instances, patients' expectations are met and high-quality healthcare that is concordant with bioethical practice is said to be the final outcome (Epstein et al., 2005; Strand, 2003; Strand, Yorkston & Miller, 1998).

The preceding literature review has thus far demonstrated that superior standards of healthcare delivery are dependent upon quality patient-centred care, quality patient-centred communication, and quality bioethical practice. As indicated by the schematic representation in Figure 1 all three of these dimensions overlap each other, and it is the contribution made by each domain that results ultimately in the perception of the quality of the overall healthcare that is rendered. If a HCP fails to utilise acceptable communication with a patient for example, his/her ability to achieve optimal patient-centred care and engage in appropriate bioethical practice may be compromised. As a result the patient may perceive the HCP's behaviour to be unsatisfactory and view the overall healthcare encounter to be less than adequate. And thus the primary prerequisite for high-quality healthcare appears to be based upon maximising interactions between patient-centred care, patient-centred communication, and bioethical practice.



**Figure 1: Schematic Representation of the Overlap of the Contributions Made by Patient-Centred Care, Patient-Centred Communication and Bioethical Practice Towards Perceived Quality of Healthcare**

Although the World Federation of Neurology recognises a wide range of disorders of the anterior horn cell, the most common form of MND is Amyotrophic Lateral Sclerosis (ALS), also called Lou Gehrig's Disease (Francis et al., 1999; Norris, Smith & Denys, 1985). Alternatively some authors have stated that ALS is a synonym for MND (Leigh et al., 2003) and appear to use these terms interchangeably when referring to the disease. For the purpose of the discussion that follows, literature using the terms MND and ALS has been utilised.

MND is a severely debilitating neurodegenerative condition, characterised primarily by the progressive degeneration and loss of motor neurons in the cerebral cortex, brainstem and spinal cord. Regardless of whether patients experience upper motor neuron and/or lower motor neuron signs and symptoms, affecting bulbar and/or limb/trunk musculature, it is inevitable that the patient will experience muscle weakness, atrophy, and spasticity of the bulbar, cervical, thoracic, and/or lumbosacral regions (Ball, Willis, Beukelman & Pattee, 2001; Francis et al., 1999; Leigh et al., 2003). As the disease progresses varying degrees of disability arise in relation to the muscles most affected, such that individuals eventually require assistance with

mobility and activities of daily living, as well as require medical and nursing care (Krivickas, Shockley & Mitsumoto, 1997). Furthermore as the ability to speak, swallow and breathe deteriorates, death usually results from respiratory failure, undernutrition, or aspiration pneumonia (Marieb, 1998; Silverstein, Stocking, Antel, Beckwith, Roos & Siegler, 1991).

MND is an idiopathic disease of adulthood with onset peaking in the fifth and sixth decades of life (Chiò, Finocchiaro, Meineri, Bottacchi & Schiffer, 1999; Silverstein et al., 1991). Typically men are more commonly affected than women until the age of 70 years when the rate then becomes equal (Mitsumoto, 1997). Progression of the disease in most cases is relentless and steady, with the spread occurring in an orderly fashion such that adjacent motor neuron groups are first involved and then vertical groups. MND or ALS can be classified into four clinical subtypes: *a) classic ALS* accounts for 90% of all cases and is characterised by upper motor neuron and lower motor neuron signs and symptoms that affect both bulbar and limb/trunk musculature, *b) progressive muscular atrophy* requires the presence of lower motor neuron signs and symptoms only, affecting limb/trunk musculature and rarely brainstem innervated muscles, *c) progressive bulbar palsy* includes upper motor neuron and/or lower motor neuron signs and symptoms and affects bulbar musculature only, and *d) primary lateral sclerosis* consists of upper motor neuron findings only, affecting limb/trunk and/or bulbar musculature (Francis et al., 1999). Presently the etiology of MND remains unknown (Bach, 2003), although factors relating to pathogenetic mechanisms, autoimmunity, oxidative stress, and cytoskeletal abnormalities have been suggested (Francis et al., 1999). Despite the uncertainty of these factors however, there is certainty that the onset of MND brings with it a poor prognosis that usually results in death within one to five years of diagnosis (Walling, 1999).

Whilst the physical presentation depends on the predominant type and location of motor neurons involved, a wide variety of signs and symptoms are characteristic of MND and usually occur in the presence of clinically intact cognition (Francis et al., 1999). Table 1 highlights some of the most common signs and symptoms experienced. Of relevance to the present study however and therefore emphasised in more detail are the signs and symptoms arising from the resulting communication impairment, given the potential influence that health communication appears to have

on perceived quality of healthcare. Approximately 80% of persons with MND develop bulbar signs and symptoms during the course of the illness, and experience impaired verbal communication (Francis et al., 1999; Leigh et al., 2003). The presence of both upper motor neuron and lower motor neuron involvement results in a mixed spastic-flaccid dysarthria that becomes more severe as the disease progresses (Kent et al., 1992). Given that upper motor neuron and lower motor neuron involvement varies among individuals, it is unpredictable as to which signs will predominate in any given case and what changes will prevail throughout the course of the disease (Love & Webb, 2001). Hypernasality is however the most common sign and usually presents early in the disease, along with reduced vocal intensity. In terms of phonation, patients often present with a strained vocal quality associated with low pitch. The harshness present in MND is often associated with a wet, gurgly vocal quality. Other patients may however show more bulbar signs with poor vocal fold adduction resulting in breathiness and short phrases. Monotony of pitch and loudness, and reduced stress is also common in this patient population, as well as audible inspiration (Bach, 1993; Francis et al., 1999; Kent et al., 1991; Kent et al., 1992; Leigh et al., 2003; Love & Webb, 2001). While most individuals are able to phonate even in the advanced stages of MND, 30% show impairment in vocal fold adduction (Francis et al., 1999). As weakness and spasticity of the oral and laryngeal musculature increases, articulation is usually characterised by imprecise consonant and vowel productions, specifically in terms of phoneme distortions. Sound production is affected further by a slow speaking rate and reduced range of movement of the articulators. In addition speech production is also compromised by reduced vital capacity, causing inadequate breath volumes for normal phrase length. In view of these compromising factors, imprecise phoneme production, hypernasality, harsh vocal quality, and slowed speech rate all have a significant impact on speech intelligibility, which declines rapidly over a short period of time. In contrast to the devastating effect that MND has on the speech of individuals, the expressive and receptive language abilities of these persons is however said to remain relatively intact (Bach, 1993; Francis et al., 1999; Kent et al., 1991; Kent et al., 1992; Leigh et al., 2003; Love & Webb, 2001).

**Table 1: Common Signs and Symptoms Associated with MND (adapted from Francis et al., 1999; Leigh et al., 2003)**

Common Symptoms	Common Signs
<ul style="list-style-type: none"> <li>▪ Cramps</li> <li>▪ Spasticity</li> <li>▪ Excessive yawning</li> <li>▪ Sialorrhoea (drooling)</li> <li>▪ Excessive secretions</li> <li>▪ Emotional lability</li> <li>▪ Anxiety</li> <li>▪ Respiratory distress</li> <li>▪ Laryngospasm</li> <li>▪ Constipation</li> <li>▪ Pain</li> <li>▪ Insomnia</li> <li>▪ Depression</li> <li>▪ Choking during meals</li> </ul>	<ul style="list-style-type: none"> <li>▪ Increased respiratory rate</li> <li>▪ Decreased chest movement</li> <li>▪ Weak cough</li> <li>▪ Sweating</li> <li>▪ Tachycardia</li> <li>▪ Weight loss</li> <li>▪ Confusion</li> <li>▪ Abnormal nocturnal movements</li> <li>▪ Fatigability of muscles</li> <li>▪ Dysphagia</li> <li>▪ Reflux</li> </ul>

For most of the twentieth century MND has occupied a paradoxical position in medical science. On one hand celebrities such as Lou Gehrig have given the disease widespread publicity, while on the other hand it is a disease that affects fewer patients than any other neurodegenerative condition and consequently attracts few researchers (Oldendorf & Bruijn, 2004). As a result the management or care of persons with MND is a complex issue because the disorder remains incurable and relies on symptom-based treatment to attend to its multifaceted nature (Traynor, Alexander, Corr, Frost & Hardiman, 2003). MND management is said to comprise two treatment options, namely a disease-specific approach or a patient-specific approach. In addition a combination of these two approaches can also be adopted. Disease-specific therapy incorporates pharmacological interventions that alter the progression of the disease and improve life expectancy (Miller, Sufit, Mitsumoto, Gelinas & Brooks, 1997). For example the drug Riluzole is a benzothiazole derivative and a common treatment option for MND because of the complex effects that it has on glutamate neurotransmission. Various clinical trials have shown that the treatment improves survival at 12 and 18 months, although the survival gain beyond 18 months is unknown. While many neurologists question the clinical usefulness of Riluzole, European MND specialists favour the use of the drug with its major benefit being perceived in terms of the hope that it provides patients (Leigh et al., 2003). Alternatively a patient-specific approach is aimed at alleviating the complications that

arise from MND, as well as increasing autonomy, improving comfort, enhancing quality of life, and providing choice about intervention (Miller et al., 1997).

Against the backdrop of disease-specific and patient-specific treatments, the multifaceted nature of MND deems coordinated team intervention the cornerstone of management for this population (Leigh et al., 2003). Team intervention is recognised as the optimal approach to quality healthcare and it involves the bringing together of the knowledge and skills of individuals from many disciplines, so as to ensure that complex problems receive comprehensive attention (Golper, 2001; Ross & Deverell, 2004a; Scambler, 1997 as cited in Ross & Deverell, 2004a). More specifically the literature supports a multidisciplinary model of team intervention for the management of MND (Gelinias, 1997, Leigh et al., 2003). A multidisciplinary approach whereby multi-professional expert teams offer effective and efficient rehabilitation, reportedly heightens a patient's morale and provides him/her with the strength to deal with the debilitation of MND (Gelinias, 1997). In this type of approach HCPs work side by side each other with clearly defined roles and attend to different aspects of a given problem. Consequently the involvement of multiple HCPs to address the multiple signs and symptoms of MND, offers persons with the disease the best possibility of enhancing their well-being and quality of life (Gelinias, 1997; Leigh et al., 2003; Traynor et al., 2003; Wade, Gage, Owen, Trend, Grossmith & Kaye, 2003).

According to the King's MND Care and Research Team in London, the coordinated team approach for acceptable management of MND requires a wide variety of HCPs to meet the many needs of the individual affected by the disease (Leigh et al., 2003). Figure 2 thus documents the ideal team composition for the management of MND, as recommended by the King's Care and Research Team. However irrespective of the benefits of multidisciplinary intervention, the success of any team approach is not guaranteed. Effective team management relies on excellent communication between HCPs, and how well these professionals help their patients and families depends largely on how well communication is managed within the group (Golper, 2001). Coordination and collaboration are thus key components of teamwork, and contribute to the quality of healthcare that is provided (Bliss & While, 2003; Leigh et al., 2003). Without effective communication between all members of the team, the functioning

of the group runs the risk of becoming disjointed and possibly even harmful to the patient and his/her family (Ross & Deverell, 2004a).

<b>Team Composition</b>	
▪ Care coordinator	▪ Home carers (usually spouse)
▪ General practitioner	▪ Nurse specialist
▪ Speech & language therapist	▪ Occupational therapist
▪ Physiotherapist	▪ Dietician
▪ Social worker	▪ Consultant neurologist
▪ Consultant in rehabilitation	▪ Palliative care team
▪ Consultant respiratory physician	▪ Respiratory technicians
▪ Interventional radiologist (for radiologically inserted gastrostomy)	▪ Gastroenterologist (for percutaneous endoscopic gastrostomy)
▪ Psychology support team	▪ Family & child counselling team
▪ Neuropsychologist	▪ Neuropsychiatrist
▪ Voluntary association staff	▪ Volunteer helpers

**Figure 2: Ideal Team Composition for the Management of MND (Leigh et al., 2003:39)**

In South Africa the “official” healthcare providers include physicians, nurses, dentists, pharmacists and supplementary care providers. Supplementary care providers otherwise known as allied medical professionals, include rehabilitative therapists such as speech-language pathologists, physiotherapists, occupational therapists and audiologists, as well as psychologists and radiologists. For many of these professionals however, the ability to engage in a team approach is challenged by the pressures of the South African healthcare system. Factors such as a lack of resources, fragmentation in the healthcare sector and inadequate referral systems, mean that the ideals of team practice documented in international literature may not apply to the South African healthcare context. It is not uncommon in South Africa for one HCP to take on the responsibility of two or three other practitioners. For example one may find a medical professional taking on both the psychological and social aspects of a particular case. It has therefore been suggested that in order to overcome some of the challenges inherent to the current healthcare system, South African HCPs require a basic understanding of what other professionals do and offer, and should accept the fact that they may be called to act beyond their scope of expertise as well as share their knowledge and skills with other disciplines (Ross & Deverell, 2004a). Thus in the case of the management of MND it may be necessary for South African HCPs to look beyond the global texts that document ideal



management for MND (i.e. multidisciplinary intervention), and begin considering an alternative model of team intervention that not only draws on the knowledge and experience of international counterparts, but is also suitable to the challenges of the present healthcare setting.

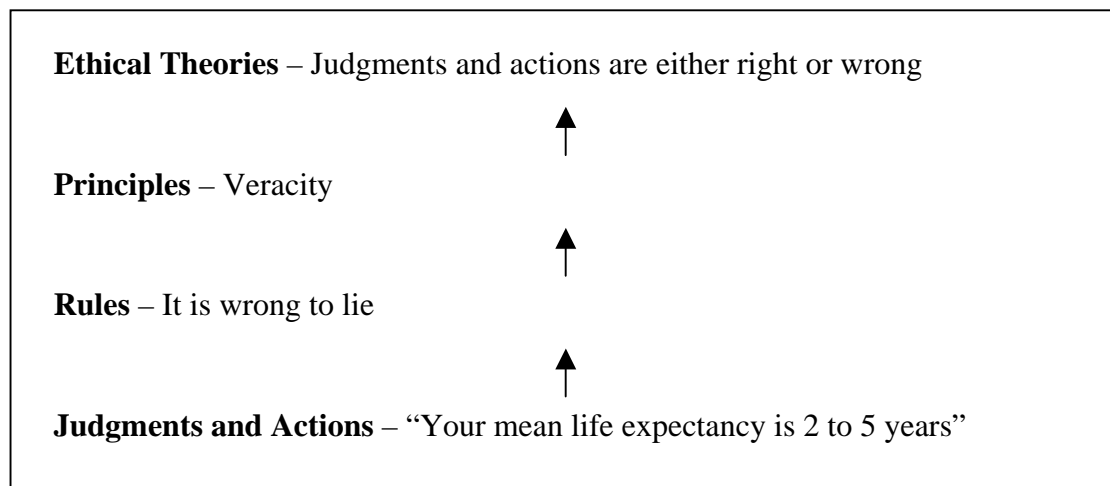
Since no one discipline or professional can meet in full the needs of a patient and his/her family members, collaboration with other HCPs is paramount (McGonigel, 1994 as cited in Ross & Deverell, 2004b). However regardless of the type of team approach adopted or the context in which intervention occurs, patients do not exist in isolation but instead are products of an interaction between their personal characteristics, the physical environment, and relationships formed with other people (Rubble, 1999 as cited in Ross & Deverell, 2004b). Thus in accordance with systems theory, an individual is part of multiple subsystems that influence each other in multidirectional ways. For most persons the family is the fundamental subsystem within which people interact, and it therefore plays an enormous role in the life of any individual (Lubinski, 2001). Since the patient is viewed as part of a wider circle of friends and family within a cultural and environmental setting, the planning and delivery of healthcare should therefore meet the needs of both this individual and his/her family subsystem (Newbury, 1991). In the context of healthcare, it is therefore both the patient and his/her family members that lie at the centre of any team (Bliss & While, 2003). Hence within a framework of patient-centred care and team intervention, the importance of the ecology of the patient needs to be held central to the overall management process, in order to meet the expectations of the system in question.

In light of the fact that MND is a progressive disorder which compromises physiological systems that are vital for sustaining life, part of team intervention includes affected individuals having to make important decisions regarding various management options. For example choices need to be made about life sustaining therapies such as respiratory support and enteral feeding, as well as the timing of palliative care (Francis et al., 1999). However because of the progressive nature of the disease, individuals with MND and their family members are given some time from the date of diagnosis to think about the disease and its treatment options, as well as discuss their thoughts, feelings and opinions with each other and the relevant

HCPs. In theory individuals should therefore be given the opportunity to make informed decisions with regard to the management that they choose to receive (Silverstein et al., 1991). In order to ensure that individuals are however informed, it is the ethical responsibility of HCPs to disclose all relevant information and respect the choices made by patients (Hunt, 1991). Fundamental to the ethical patient-professional relationship, lies respect for the patient and the provision of a sense of autonomy for the individual concerned (Joffe, Manocchia, Weeks & Cleary, 2003). In the case of MND the ethical obligations and responsibilities bestowed upon the relevant HCPs are no different to any other healthcare situations, and persons with the disease reportedly welcome the opportunity to discuss end-of-life issues and express their desire to participate in the decision-making process (Benditt, Smith & Tonelli, 2001; Silverstein et al., 1991). However for many healthcare consumers and professionals alike, it is all too familiar that the decision-making process is not always a simple task. In certain cases where individuals are incompetent, such as Alzheimer's disease, a troubling ethical problem arises in that the HCP is required to establish the patient's treatment wishes but reliable communicative interactions may not be possible. Revealing the patient's autonomy and ascertaining certainty about the integrity of decisions made, is therefore a complex process (Smyth, Riedl, Kimura, Olick & Siegler, 1997). However while one may assume that this type of ethical problem is not experienced in MND because of persons' relatively intact cognition and language, it is unknown what impact impaired communication may have on an individual's ability to convey his/her preferences and decisions regarding management. As a result the ethics surrounding the decisions that are taken for persons with MND is questionable, and it is thus unclear whether individuals' autonomy and right to self-determination is being acknowledged.

In order to address various ethical concerns Beauchamp and Childress (1989 as cited in Strand et al., 1998) suggest a hierarchical approach to moral reasoning entitled "levels of moral justification". They state that in order to engage in moral reasoning different levels of abstraction must be applied. The first or lowest level of the hierarchy pertains to judgements and actions, and refers to decisions that are made about a particular action. The second level relates to rules and states that certain actions may or may not be performed depending on whether or not they are right or wrong. Principles serve as the foundation to rules, and thus comprise the third level

of the hierarchy. Moreover principles are regarded as general and fundamental in nature. The fourth and final component of the hierarchy relates to theories in which the systematic relationship of principles and rules are considered. Strand et al. (1998) provide the following example to depict each level of the hierarchy (Figure 3). At the top level an ethical theory is deontology for example, which states that judgments and actions are either right or wrong irrespective of the consequences. A principle derived from this theory is veracity, where it is right to tell the truth. This principle in turn provides the foundation for the rule which may state that it is wrong to tell a lie. Finally the action exemplifying the principle and rule is for example the general practitioner who decides to tell a patient that his/her mean life expectancy is two to five years, following a diagnosis of ALS.



**Figure 3: Levels of Moral Justification (Strand et al., 1998:193)**

The two most common bioethical theories include deontology and teleology or consequentialism (Beauchamp & Childress, 1989 as cited in Strand et al., 1998; Beauchamp & Childress, 1994). The central tenet of deontology is that a moral person must always act in accordance with his/her duties (Seedhouse, 1998), and a moral person is one who follows the social conventions about right and wrong human behaviour (Horner, 2003). From a deontological perspective a person should therefore perform his/her duties without exception and regardless of the consequences, because “right” actions are not determined by whether or not they will produce “good consequences”. The theory of consequentialism on the other hand asserts that “the end justifies the means” (Beauchamp & Childress, 1989 as cited in

Strand et al., 1998; Beauchamp & Childress, 1994). According to Bentham (1970 as cited in Beauchamp & Childress, 1994) an individual should attempt to achieve the greatest good, happiness or number, and in doing so the action will be justified if it results in more good than any other action undertaken. While these two theories appear to provide a philosophical basis upon which to approach ethical problems, Beauchamp and Childress (1994) suggest that bioethical practice usually relies on a principle-based approach to guide moral decision-making. Principle-based ethics operates according to the use of various principles, which are essentially general guides that leave considerable room for judgements in particular cases. There are four major principles central to bioethics, including autonomy, non-maleficence, beneficence and justice. In addition to these principles there are three minor secondary components that also consume a large part of bioethical practice. These minor principles include fidelity, veracity and confidentiality (Beauchamp & Childress, 1994). While these concepts are discussed in detail in the following chapter, it should be noted that although both the major and minor principles offer general moral injunctions to some ethical issues, they have been criticised because they do not provide precise guides that inform actions in a particular circumstance (Beauchamp & Childress, 1994; McLeod, 1994).

In acknowledging the various theories and principles that are available for engaging in the process of moral reasoning, some HCPs may assume that such knowledge and understanding is beyond the scope of their practice. Since medical ethics has developed in part to the increase in medical technologies that have allowed healthcare providers to push the limits at the beginning and end stages of life, public concern regarding the morality of medicine and healthcare has become very topical (Foye, Kirschner, Brady Wagner, Stocking & Siegler, 2002). The dramatic life and death responses in emergency rooms and intensive care units have placed much of the emphasis of medical ethics on doctors and specialists, while little attention has been given to other HCPs. It is only in recent times that the spotlight has been placed on the moral questions that confront rehabilitation professionals caring for individuals with disabilities and chronic illness (Sim, 1997). Of late the therapy professions have therefore initiated a keener interest in the ethical considerations and implications of their practice, acknowledging that while the ethical issues that arise in rehabilitation are much less topical and immediate in nature relative to euthanasia and abortion for

example, they are nonetheless fundamental to high-quality healthcare (Foye et al., 2002; Sim, 1997). According to Sim (1997) ethical considerations should thus be of significant concern to all HCPs because such individuals usually function as members of a professional team, and a key characteristic of such an occupational group is the presence of guiding ethical principles for professional practice. In addition the strongest argument for a moral basis in healthcare lies with the concept of health itself. While factors such as money, knowledge and status are important, health seems to take precedence and it is a precondition for almost anything else of importance. The activities of the therapy professions are thus of particular value because they are associated closely with the functional capabilities of an individual, and it is the integrity of these functions that determine much of what the individual is able to achieve in life (Sim, 1997).

It is thus clear that all HCPs are obliged to render quality healthcare services that are ethically sound. And for this reason it is important that all HCPs familiarise themselves with the various theories and principles that exist to facilitate the process of moral reasoning (Foye et al., 2002). Furthermore these same ethical responsibilities and principles that govern medicine are also available to assist HCPs in resolving the ethical complexities surrounding MND management. However notwithstanding the theories and principles that exist for the purpose of moral reasoning, the question arises as to how HCPs elicit and reveal the concerns and preferences of their patients with MND who are communicatively impaired, so as to offer these individuals an opportunity for self-determination. Although one may be quick to suggest that effective communication between the patient and the professional can overcome such challenges in healthcare, and indeed there is a significant relationship between practitioners' communication behaviours and patients' health outcomes (Arora, 2003), the fact that the person with MND is likely to be communicatively impaired contributes an additional variable to this system. A vast amount of emerging literature suggests that communication abilities are the most important skills required in the patient-professional relationship, and studies are now providing strategies to enhance the communication skills of practitioners (Arora, 2003, Bensing, 2000; Tilden, Tolle, Garland & Nelson, 1995). However the content of such literature looks at aspects such as the HCP's compassion and honesty, as well as his/her frequency of visits with the patient and availability to attend to the patient's

needs. A paucity of information exists that documents healthcare consumer-professional interactions when the patient presents with a significant communication impairment, and how this impairment may impact on the overall management process. Given however that overlap does exist between patient-centred care, patient-centred communication, and bioethical practice as depicted in Figure 1, it is thus possible that if ineffective communication between the patient and professional occurs in view of the communication impairment, any of these dimensions may be compromised and the patient's perception regarding the overall quality and ethical nature of MND care may be adversely affected.

In the healthcare setting patients who have difficulties engaging in the spoken and/or written language modalities may thus be excluded unnecessarily from informed decision-making and the provision of consent for example. Adequate communication abilities are therefore fundamental to patient autonomy, and not only contribute to improved healthcare but also enhance quality of life for all individuals with MND (Bach, 1993; Francis et al., 1999; Leigh et al., 2003). While it is not the role of the speech-language pathologist to determine a patient's decision-making capacity, it is this very professional who is most often able to assist in the process of self-determination (Brady Wagner, 2003; Pannbacker, Middleton & Lass, 1994). Moreover although the same ethical issues that any other patient may encounter are also likely to affect individuals with diminished communicative competency, these individuals are inherently more vulnerable to losing their self-determination and capacity to make authentic decisions. Speech-language pathologists thus play an especially important role in not only promoting the communicative abilities of communicatively impaired individuals, but also in protecting and advocating for the rights of these patients (Brady Wagner, 2003). Consequently of particular relevance to the present study is the importance of effective communication and the fact that it is a prerequisite for individuals when participating in society, healthcare and life in general, as well as experiencing satisfaction in this regard (Simmons-Mackie, 2001),

In order to improve and/or safeguard the quality and ethical nature of healthcare with regard to the management of MND, it therefore seems apt to suggest that by eliciting the perceptions of healthcare consumers in terms of patient-centred care, patient-centred communication, and bioethical practice, the requirements necessary for

enhancing service delivery to this patient population may be revealed. Moreover while the literature confirms the importance of eliciting patients' perceptions about their treatment experiences in order to investigate consumer satisfaction and the outcomes of healthcare delivery (Arora, 2003; Stewart, 2001), no literary findings could be located that establish the perceptions of persons with MND regarding the management that they receive. Investigating the perceptions of persons with MND with regard to medical and rehabilitative management is therefore well justified in an attempt to enhance healthcare for this population. However if one hopes to achieve improved service delivery to persons with MND and their families, one needs to appreciate that although the elicitation of healthcare consumers' perceptions will certainly inform the changes necessary for improvement, such ideals are only likely to be realised within the reality of the current healthcare setting. By virtue of the socio-political changes that have reformed many of the world's healthcare systems, and the financial challenges faced by many service providers and healthcare funders (Hallowell & Chapey, 2001; Pietranton, 1998), patients' perceptions of healthcare alone are simply not practical for determining optimal management practice. Ideal management needs to be considered against a backdrop of the current issues and challenges inherent to healthcare service delivery. On this basis while eliciting the healthcare consumers' perceptions regarding the medical and rehabilitative management of MND will go a long way towards understanding the steps needed to be taken to improve healthcare for this population, such ideals are likely to only be assimilated into a healthcare system if they are compatible with the standards and trends that govern current clinical service delivery.

On this basis ideal management needs to be based on reality, and the trends in current clinical service delivery need to be understood and acknowledged. In response to the dramatic upward spiral of healthcare costs throughout the world, for the last two decades healthcare funders have realised the need to implement strategies to ensure cost effective service delivery. Managed care frameworks of service delivery have therefore become a trend in healthcare around the globe (Hallowell & Chapey, 2001). The ultimate goal of a managed care approach for service delivery is to shift the financial risk from the payer to the healthcare provider. However managed care is not merely a different healthcare funding strategy, it is an entirely novel framework of service delivery with different rules that govern its practice (Pietranton, 1998). A

comparison of the principles of traditional service delivery versus those of managed care can be found in Table 2. Thus whilst managed care functions primarily to achieve cost effective management, it also aims to provide access to care for all individuals and enhance the quality of services rendered. In restructuring healthcare systems to achieve such cost effectiveness, the control of access to care and the duration of care has been transferred from healthcare providers to healthcare funders. In doing so however, patients' access to care and the quality of care has unfortunately been placed at risk. As a result healthcare providers have been challenged and forced to act as a "middleman" between patients who expect quality healthcare, and healthcare funders who demand cost effective intervention (Hallowell & Chapey, 2001; Pietranton, 1998). Specifically the challenges faced by most HCPs in terms of managed care include a) healthcare consumers' access to services, b) the quality, intensity, duration, and frequency of care provided, c) the livelihood of professionals, and d) the maintenance of the each profession's integrity (Hallowell & Chapey, 2001).

**Table 2: A Comparison of the Principles of Traditional Service Delivery Versus Those of Managed Care (Pietranton, 1998:671)**

Traditional Service Delivery	Managed Care Service Delivery
<ul style="list-style-type: none"> <li>▪ Retrospective reimbursement</li> <li>▪ Financial risk on payer</li> <li>▪ Per visit/procedure payment</li> <li>▪ Authorisation is needed</li> <li>▪ Provider-driven system</li> <li>▪ More visits/procedures generate more charges (i.e. more potential revenue)</li> <li>▪ Payer wants provider to do as little as possible (control costs)</li> <li>▪ Provider wants to do as much as clinically justified</li> </ul>	<ul style="list-style-type: none"> <li>▪ Prospective reimbursement</li> <li>▪ Financial risk on provider</li> <li>▪ Capitated rate for covered population</li> <li>▪ Clinical autonomy</li> <li>▪ Payer-driven system</li> <li>▪ Fewer visits/procedures reduce costs (i.e. more potential profit)</li> <li>▪ Payer wants provider to do everything possible</li> <li>▪ Provider wants to provide minimum services necessary (control costs)</li> </ul>

An additional factor relating to managed care includes treatment outcomes (Tompkins & Lustig, 2001). In the American marketplace the phrases "satisfaction guaranteed", "money back warranty", and "the best value for your dollar" have become commonplace (Pietranton, 1998). It is no longer acceptable for healthcare providers to show simply that their treatment is effective without also demonstrating the cost



involved versus the benefits derived. Healthcare funders are no longer interested in paying for clinical services without the certainty of “buying” measurable outcomes. Consequently healthcare providers are therefore being asked to provide proof of the measurable value of their services (Pietranton, 1998; Tompkins & Lustig, 2001). Evidence-based medicine has thus become a dominant paradigm in modern medicine, and involves the integration of individual clinical expertise and external scientific evidence, so as to offer HCPs the best available evidence about the most appropriate treatments for their patients (Bensing, 2000). However as discussed earlier in this chapter, patient-centred care is also a dominant paradigm in modern medicine. While both of these approaches are reportedly essential to clinical decision-making and quality healthcare practice, Bensing (2000) states that they share little commonality between one another. Firstly evidence-based medicine is disease-orientated and not patient-centred. It relies on the “good standard” of randomised clinical trials to find evidence, thereby ignoring the diversity of symptoms between patients and the diversity in the way that patients evaluate and cope with these symptoms. In addition evidenced-based medicine relies on the HCP’s agenda and his/her knowledge gained from scientific research on homogeneous populations, and does not tap the individual patient’s unique experiences and preferences. On the other hand patient-centred care places emphasis on patient participation in clinical decision-making and meeting patient’s individual needs. A paradox thus arises in the sense that although evidence-based medicine offers patients high-quality care and protects them from questionable treatments, patient-centred care may come under threat when patients’ personal perspectives are bypassed. And without patient-centred care, medicine comes under threat of losing its humane face and being reduced to mere technology, paper guidelines, and statistical figures (Bensing, 2000). As a result Bensing (2000) suggests that in order to integrate these two paradigms, such that evidence-based medicine becomes more patient-centred and patient-centred care becomes more evidence-based, health communication and communication research is necessary. Since the best way of knowing a patient’s story is to listen to his/her agenda, and at present there is no other means of establishing what a patient’s preferences will be, it follows that communication is the royal pathway to patient-centred care. Hence the key to strengthening the evidence base of patient-centred medicine lies in health communication. For example evidence-based medicine can reportedly become more patient-centred by incorporating patients’ preferences in randomised clinical trials,

while patient-centred care can become more evidence-based through more focused study designs that pay specific attention to communication. Thus whilst patient-centred care and evidence-based medicine are important components for quality healthcare, communication between healthcare consumers and HCPs has the potential to bridge the gap between clinical practice and clinical science (Bensing, 2000).

### **1.3 CONCLUSION**

As a result of the paradox between patient-centred care and evidence-based medicine (Bensing, 2000), as well as the requirements of modern medicine in general, it thus appears that the stakes have been raised for present-day HCPs. A need is apparent for HCPs to strike the optimum balance between a multitude of factors in order to ensure that healthcare service delivery is of a high standard, bioethical in nature, and satisfactory to all healthcare consumers, healthcare providers and healthcare funders. In achieving a balance between patient-centred care, patient-centred communication, and bioethical practice, as well as acknowledging the significance of revealing patients' perceptions regarding management in order to inform change within clinical service delivery (Sullivan, 2003), the value of evidence-based medicine must not be overlooked as to the vital contributions that are made towards medical science (Bensing, 2000). However to ensure that management which is informed by a combination of patients' perceptions and evidence-based medicine has the potential to be assimilated into the present healthcare system, current trends in clinical service delivery need to be considered. Moreover in accordance with models of managed care, management must not only be cost effective and accessible to all healthcare consumers, but also its outcomes must be clearly beneficial and measurable so as to enhance further the quality of clinical service delivery (Pietranton, 1998).

Thus in view of the devastating effect that MND has on both the patient and the family system (Trail, Nelson, Van, Appel & Lai, 2003), as well as the perceived dissatisfaction and challenges regarding healthcare in South Africa (Beck & Falkson, 2001), the present study investigated the perceptions of persons with MND and the perceptions of their caregivers with regard to current medical and rehabilitative management of the disease. Attention was given to the resulting communication impairment and how this may have influenced participants' perceptions, given that effective patient-centred communication has the potential to alter patient-centred care,

bioethical practice, and thus the perceived quality of overall healthcare. Moreover by considering clinical service delivery through exploring the perceptions of healthcare consumers regarding the medical and rehabilitative management of MND, it was anticipated that areas in need of improvement or change would be highlighted for HCPs, healthcare organisations, and speech-language pathologists in view of the significant influence that communication has on the quality of healthcare. Furthermore by acknowledging areas of improvement or change that healthcare consumers perceived to be necessary for enhanced management of MND, in relation to considering the limitations and restrictions that are placed upon the current healthcare setting, the next step towards achieving high-quality healthcare for this catastrophic condition was envisaged. Also whilst the present study in no way proposed to raise solutions for resolving the current challenges of healthcare in South Africa, it did propose to better understand healthcare consumers' perceptions and experiences relating to the management of MND, and raise implications for enhancing service delivery to this patient population. Finally given the dramatic transformations that have occurred in healthcare across the globe (Pietranton, 1998), and the realisation by some HCPs that it is time for a new beginning in ALS (Brooks, 1999), it seems only fitting that efforts are made to investigate MND management in order to initiate change. Moreover a need arises to improve clinical service delivery for MND healthcare consumers in order to rectify the fact that *“Management in this country is feeble because medical people are not professional and give up on you too easily. All we wanted was support and to know that he actually cared”* (Participant in this Study).

## **CHAPTER TWO**

### **METHODOLOGY**

#### **2.1 AIMS**

##### **2.1.1 Main Aim**

To investigate the perceptions of persons with MND and the perceptions of their caregivers<sup>1</sup> with regard to the medical and rehabilitative management received on and following diagnosis.

##### **2.1.2 Sub-Aim**

The following sub-aim was formulated in order to address the main aim:

1. To explore the perceptions of persons with MND and the perceptions of their caregivers with regard to the role that the communication impairment may have on healthcare.

#### **2.2 RESEARCH DESIGN**

An exploratory research design was employed for this study as the researcher was unable to manipulate any independent variables, there was no control over extraneous variables, and participants could not be assigned randomly to different test conditions (Pannbacker & Middleton, 1994). Thus the research design did not allow for experimental investigation to be conducted, but rather facilitated the process of exploring, analysing, and describing the research topic in detail (Pannbacker & Middleton, 1994).

Specifically the exploratory design that was utilised for this project was the "case study" method. Although case study research has been criticised for its expansionistic rather than reductionistic nature, which contributes to proliferation rather than a searching for and refining of the essences and ingredients that build theory, its exploratory power does allow for deep probing and intensive analysis of a phenomenon occurring in one's life that is individual, holistic, and based on actual practice (Lewis, 2003). The case study design is therefore invaluable in that it allows for in-depth information to be explored and analysed in the specific context of the research (Lewis, 2003; Stake, 1978). Furthermore whilst case studies do not allow for generalisation, or correlations or causal relationships to be established, they are

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<sup>1</sup> In this context caregiver refers to any family member, significant other individual, or trained individual that cares for the person with MND on a regular basis.

appropriate for obtaining powerful stories about the research topic in order to illustrate a specific social context (Doehring, 1996; Grbich, 2003). Thus, since the limited number of persons with MND and the heterogeneity of this population deemed a large experimental design inappropriate, the case study method allowed for a great deal to be learnt from a few exemplars of the phenomenon in question (Patton, 1987). In addition the researcher selected a parallel case study design as opposed to a single case study, because no one perspective can provide a full account of the experiences pertaining to the research discourse (Doehring, 1996; Grbich, 2003). Multiple single case studies therefore offer a more holistic, comprehensive, and contextualised understanding of the research topic (Lewis, 2003). Consequently this study employed a collective case study design, where six detailed parallel case studies were performed in order to gather the necessary data to address the research question.

The multiple parallel case studies followed a cross-sectional design in that each participant was involved in one episode of data collection, as opposed to gathering data over a period of time (Drummond, 1996). Thus in the present study, although all participants were at different stages of disease progression they were all studied at the same point in time. Despite longitudinal studies being more effective for generalising findings from a small sample to the broader population, and for studying change over time (Drummond, 1996; Lewis, 2003), the researcher did not wish to focus on change *per sé*, but rather explore the broader context within which change occurs so as to capture a set of factors that participants perceived as contributing to the medical and rehabilitative management of persons with MND.

Finally the research design fell within a predominately qualitative research paradigm, involving the use of in-depth interviewing. Although a small quantitative component was included by virtue of a motor speech assessment that relied on numerical evaluation, the aim of this section was to assist in quantifying the communication impairment of the sample participants rather than for data capturing *per sé*. Thus in spite of this small quantitative aspect of the design, the researcher did not wish to employ a multi-method study because although one may be tempted to assume that a dual qualitative-quantitative paradigm of data collection yields more information, the quality of data capturing and data analysis should not be sacrificed for the quantity of data collected (Silverman, 2000). In addition Silverman (2000) states that although

qualitative research has been criticised as a “soft” science and labelled as exploratory only with little scientific rigour, quantitative data in the form of formal statistics is simply inappropriate to some aspects of social science or everyday situations. Hence while quantification is often useful, it sometimes conceals fundamental social processes (Silverman, 2000). In saying this however, qualitative research does run the risk of threats to reliability and validity, and is susceptible to fallacies of interpretation. On this basis in the absence of scientific vigilance and rigour, a qualitative study’s significance may be limited severely (Silverman, 2000; Stake, 1978). In light of these concerns the present study therefore employed a variety of strategies as discussed towards the end of this chapter under the sections on reliability and validity, in order to protect and enhance its scientific rigour. Reliability is after all not about the choice made between a study using numbers or one using words, but rather about a pragmatic decision that is best suited to investigating the research topic. No one specific methodology can offer automatic protection from rigorous, critical standards that must apply to any enterprise concerned with sorting “fact” from “fancy” (Hammersley, 1992 as cited in Silverman, 2000; Silverman, 2000).

## **2.3 RESEARCH PARTICIPANTS**

The term “Unit” was adopted to describe the person with MND and all other individuals encompassed within his/her ecological system. Such individuals referred to those who were involved in the direct management or care of the person with MND, and included medical HCPs (e.g. general practitioner and neurologist), allied medical or rehabilitative professionals (e.g. physiotherapist and psychologist), non-medical or alternative professionals (e.g. homeopath and Reiki healer), and caregivers (i.e. family members, significant other individuals such as friends, and individuals trained as formal carers).

### **2.3.1 Participant Inclusion Criteria**

#### **2.3.1.1 The Person with MND**

Persons with MND were selected for the study based on the following criteria:

1. A diagnosis of MND based on a neurologist’s expertise, regardless of the clinical subtype or stage of progression of the disease.

2. The presence of a communication impairment regardless of the degree of severity, as reported subjectively by the recruiting agent, person with MND, or caregiver.
3. The presence of one caregiver who was willing and able to participate in the study.
4. First language English or Afrikaans speakers because the importance of knowing the language of the interviewee is essential for asking understandable questions and interpreting the responses accurately (Berg, 1989). In addition interviews conducted in the interviewee's primary language minimises threats to the validity of responses arising from cultural factors (Helman, 1984).
5. The approval of the recruiting agent that in his/her opinion the person with MND was capable from an emotional and psychological standpoint to participate in the study.

#### **2.3.1.2 Members of the Unit**

Members of the Unit who were required to participate in the study did not include HCPs or alternative professionals, but rather individuals who were involved in caring for the personal needs of the person with MND (e.g. activities of daily living). Caregivers were thus selected for the study based on the following criteria:

1. He/she had been involved directly in the management and care of the person with MND on a regular basis (i.e. involved at least three to four days per week), and knew the person relatively well (i.e. involved for at least one month prior to participation in the study). Such criteria were adopted to ensure that this member of the Unit had had sufficient opportunity to observe and formulate his/her own perceptions with regard to the general management practices of MND, prior to engaging in the study.
2. First language English or Afrikaans speakers for the same reason documented for the person with MND.

#### **2.3.2 Participant Exclusion Criteria**

##### **2.3.2.1 The person with MND**

Persons with MND were excluded from the study based on the following criteria:

1. Individuals who presented with a concomitant neurological and/or psychiatric illness which may have predisposed them to additional physical,

communicative and/or cognitive deficits, and thus operated as a confounding variable within the study. Concomitant neurological and/or psychiatric illness was determined by confirmation from the neurologist, and/or subjective reports from the recruiting agent, person with MND, or his/her caregiver.

2. The presence of a premorbid history of communication impairment (e.g. stutter), as the sub-aim formulated for this study was to investigate healthcare with respect to the communication impairment experienced in MND alone, and not as a combination of communication impairments. Prior communication history was established through subjective reports provided by either the person with MND or his/her caregiver.
3. The presence of any physical disabilities unrelated to MND, as the researcher aimed to minimise additional variables that persons may have perceived as impacting on their management, although not relating directly to the experience of MND.

#### **2.3.2.2 Members of the Unit**

Caregivers were excluded from the study based on the following criteria:

1. He/she presented with a disability (e.g. communication impairment or hearing impairment) that may have affected the interview process. Such history was determined by subjective reports from the recruiting agent, person with MND, or the potential participant himself/herself.
2. He/she would be unreliable to participate in the study as reported by the recruiting agent or person with MND. One such factor that may have impinged on the reliability of caregivers' responses was that of denial of the presence of MND.

#### **2.3.3 Sampling Procedure**

Persons with MND that participated in the study were recruited from the MND Association of South Africa, as well as from neurologists and rehabilitative therapists known to treat individuals with MND. Recruitment occurred via a criterion sampling procedure where all individuals that met the predetermined criteria as described earlier, and consented to participation, were considered for the study (Patton, 1987).



Criterion sampling belongs to a qualitative sampling paradigm and is a form of non-probability sampling, where the sample that is selected is chosen because of features or characteristics that enable detailed exploration and understanding of the topic under investigation (Ritchie, Lewis & Elam, 2003a). Unlike quantitative probability sampling that aims to generate statistically representative samples in order to provide estimates of the prevalence or distribution characteristics that apply to the wider population (Grbich, 2003; Silverman, 2000), the aim of this study was not to determine statistically significant discriminatory variables. Rather the present sampling procedure aimed to recruit a heterogeneous sample of individuals with MND, in order to gain a detailed understanding of the phenomenon in question by generating ideas and trends, and developing explanations. Thus by recruiting samples based on meeting the predetermined selection criteria, and hence possessing specific characteristics that were salient to the study, rich and meaningful data could be yielded (Grbich, 2003).

In addition to meeting prescribed selection criteria, criterion sampling requires that the sample be as diverse as possible within the boundaries of the defined population (Ritchie et al., 2003a). Diversity maximises the opportunity to explore a full range of factors associated with the research topic, as well as allows investigation of interdependency between variables such that the most relevant variables can be detached from those of less importance (Grbich, 2003; Ritchie et al., 2003a; Silverman, 2000). Consequently the researcher recruited participants at varying stages in the progression of MND, and with varying degrees of severity in terms of the communication impairment, in order to offer the opportunity of determining trends related to variation in such variables. Although the literature acknowledges that criterion sampling limits generalisation to a larger population, provides the researcher with an opportunity for bias when conducting selection, and is devoid of the benefits of quantitative sampling (Grbich, 2003; Ritchie et al., 2003a), a qualitative sampling strategy was beneficial in this study in order to recruit a diverse sample of participants most appropriate for yielding data rich in detail. Moreover because qualitative samples are often criticised for not possessing the features of a quantitative sample (Ritchie et al., 2003a), it is essential that if one wishes to assess the quality of a qualitative sample the appropriate selection criteria must be applied,

and sampling strategies from an alternate research paradigm must be avoided (Drummond, 1996; Grbich, 2003; Ritchie et al., 2003a).

### **2.3.4 Description of Participants**

A total of twelve individuals participated in this study, including six persons with MND and six caregivers. It should be noted that from here on the term “caregiver” has been replaced by “family member” because in all but one Unit (Unit 2) a family member participated in the study and not a significant other individual or individual trained as a carer. A detailed demographic profile of each Unit is set out in Table 3.

#### **2.3.4.1 Persons with MND**

The sample of persons with MND comprised five females and one male. This sample was however not representative of the broader population of individuals with MND in view of the fact that typically men are more affected than women until the age of 70 years when the rate then becomes equal (Mitsumoto, 1997). The average age of the participants with MND was 58.9 years with a standard deviation (SD) of 9.7 years. According to Chiò et al. (1999) MND peaks in the fifth and sixth decade of life, and thus the average age of the present sample was consistent with the literature. Although Shadden (1988) states that many of the problems associated with the geriatric population are related to communication difficulties and that there is an increase in incidence of cognitive and communicative decline with age, the researcher chose to exclude age-limiting criteria that may have prevented variables of a geriatric origin from confounding the results of the study. The reason for this decision was based on recent literature which reports that there has been a gradual improvement in the overall health of the elderly, with the majority of individuals over 85 years caring for themselves. Moreover new neuroimaging and behavioural methods, as well as evolving research into the molecular study of the nervous system, have resulted in agreement between some researchers that despite a loss of neurons, the brain undergoes continuous adaptation as it ages (Chapey & Hallowell, 2001). Thus it is possible that an individual at the age of 75 years for example, may present with intact cognition and communication skills relative to a counterpart of 55 years. On this basis the oldest person with MND (Unit 6) was included in this study based on the fact that her daughter stated that although her mother’s muscles had become weak, her brain had in fact become “sharper”. In addition although formal assessments were not

conducted, by virtue of observation and interaction the researcher was able to confirm the absence of overt cognitive difficulties in all persons with MND at the time of each interview. The researcher does however acknowledge that subtle cognitive impairments may have gone unnoticed.

In terms of the diagnosis of MND, the average time from the month of confirmation of the disease with the neurologist to the month of data collection was 17.5 months (SD = 19.1 months). The average time since the onset of symptoms to the month of data collection was determined as 33.0 months (SD = 12.9 months). Thus from the onset of symptoms until the diagnosis of MND an average of 15.5 months (SD = 10.7 months) had lapsed. Gelinas (1999a) states that worldwide the mean time from onset of symptoms to confirmation of diagnosis is approximately 16 to 18 months. However due to the small sample size the statistical data of the present study should be interpreted with caution.

In terms of occupation all persons with MND had ceased gainful employment, excepting for Unit 4 where the individual was semi-employed and Unit 5 where the individual was engaged in full-time employment. In the case of Unit 6 the person with MND had never been employed premorbidly in the first instance.

With regard to physical presentation, three persons with MND (Units 1, 3 & 4) were wheelchair bound and one individual (Unit 2) was bedridden, either relying totally on or requiring assistance from a family member for all activities of daily living. The two remaining persons with MND (Units 5 & 6) were ambulatory, although the individual from Unit 6 required the assistance of a walker, as well as assistance for all activities of daily living. The person with MND from Unit 5 was completely independent and only required assistance with fine motor tasks.

**Table 3: Demographic Profile of Each Unit**

<b>PERSON WITH MND</b>						
	<b>Unit 1</b>	<b>Unit 2</b>	<b>Unit 3</b>	<b>Unit 4</b>	<b>Unit 5</b>	<b>Unit 6</b>
<b>Gender</b>	Female	Female	Female	Male	Female	Female
<b>Age in years</b>	62.5	58.5	64.5	48.9	46.8	72.3
<b>Time since diagnosis<sup>2</sup></b>	19 months	16 months	10 months	54 months	1 month	5 months
<b>Time since onset of symptoms<sup>3</sup></b>	33 months	23 months	23 months	57 months	26 months	36 months
<b>Current / previous occupation</b>	Secretarial work (no longer employed)	Nursing sister (no longer employed)	Sales executive (no longer employed)	Farmer & champion show-jumper (semi-employed)	Sales executive (full-time employment)	Housewife (no longer fulfilling previous duties)
<b>Physical presentation</b>	<ul style="list-style-type: none"> <li>▪ Wheelchair bound</li> <li>▪ No functional use of arms / legs</li> </ul>	<ul style="list-style-type: none"> <li>▪ Bed ridden</li> <li>▪ Partial use of left hand</li> <li>▪ No functional use of legs / right hand</li> </ul>	<ul style="list-style-type: none"> <li>▪ Wheelchair bound</li> <li>▪ Functional use of both hands but weakness</li> <li>▪ Limited movement of legs</li> </ul>	<ul style="list-style-type: none"> <li>▪ Wheelchair bound</li> <li>▪ Partial use of left hand</li> <li>▪ Limited movement of legs / right hand</li> </ul>	<ul style="list-style-type: none"> <li>▪ Ambulatory</li> <li>▪ Slight weakness of both hands</li> </ul>	<ul style="list-style-type: none"> <li>▪ Walks with assistance</li> <li>▪ Functional use of both hands but weakness</li> </ul>
<b>Extent others relied upon</b>	Total reliance for all activities of daily living	Total reliance for all activities of daily living	Requires assistance for all activities of daily living	Total reliance for all activities of daily living	Requires assistance with fine motor tasks	Requires assistance for all activities of daily living
<b>Living arrangements</b>	Lives with daughter and daughter's family	Lives with close friend	Lives with husband	Lives with wife and 2 children	Lives with husband and son	Lives with husband, daughter and daughter's family
<b>Current medical &amp; rehabilitative intervention</b>	GP in the event of illness	GP in the event of illness	GP in the event of illness	GP in the event of illness & consultations with PT & SLP when necessary	Regular follow-up with neurologist	Regular follow-up with neurologist & consultations with PT & SLP when necessary

<sup>2</sup> Time since diagnosis indicates the time calculated from the month of diagnosis to the month of data collection.

<sup>3</sup> Time since onset of symptoms indicates the time calculated from the month of onset of symptoms to the month of data collection.

<b><u>PERSON WITH MND</u></b>						
	<b>Unit 1</b>	<b>Unit 2</b>	<b>Unit 3</b>	<b>Unit 4</b>	<b>Unit 5</b>	<b>Unit 6</b>
<b>Current non-medical / alternative intervention</b>	-	Reflexology	Drug therapy Reiki healing	-	-	-
<b>Previous interventions</b>	SLP, PT	-	PT	Stem cell therapy Homeopathy	-	OT
<b>Feeding status</b>	Severe difficulty during all meals; soft diet	PEG	Occasional difficulty but not perceived as problematic; normal diet	Occasional difficulty; soft diet	No difficulty; normal diet	Severe difficulty during all meals; soft diet; arrangement for PEG
<b>Communication mode</b>	Non-verbal AAC (alphabet board with eye gaze)	Non-verbal AAC (computer)	Speech – unintelligible. Facilitation with written language	Speech - unintelligible. Facilitation with written language	Speech - intelligible	Speech - unintelligible. Facilitation with written language
<b><u>PARTICIPATORY MEMBER OF THE UNIT</u></b>						
<b>Gender</b>	Female	Female	Male	Female	-	Female
<b>Relationship to person with MND</b>	Daughter	Friend	Husband	Wife	-	Daughter
<b>Age in years</b>	34.7	78.3	68.9	47.9	-	47.1
<b>Current occupation</b>	Runs own business	Retired	Sales; semi-retired	Assists on farm	-	Artist
<b>Role in the Unit</b>	Provides physical, emotional & financial support	Provides physical, emotional & financial support	Provides physical, emotional & financial support	Provides physical, emotional & financial support	-	Provides physical, emotional & financial support
<b>Other members of Unit involved</b>	2 fully trained carers	-	2 fully trained carers	1 qualified intensive care nurse	-	Husband
<b>Formal training received for care giving</b>	None	None	None	None	-	None
<b>Formal communication training received</b>	None	None	None	None	-	None

GP = general practitioner; PT = physiotherapist; SLP = speech-language pathologist; OT = occupational therapist; AAC = alternate & augmentative communication, PEG = percutaneous endoscopic gastrostomy

In terms of current medical and rehabilitative intervention, two persons with MND (Units 5 & 6) attended regular and ongoing follow-up appointments with their neurologist, while the remaining participants only consulted their general practitioner in the event of illness. In addition although two individuals (Units 4 & 6) were receiving intervention from allied medical professionals in the form of physiotherapy and speech-language pathology, these consultations were not regular and only occurred when the person with MND deemed it necessary. Furthermore while two persons with MND (Units 1 & 3) had received rehabilitation following diagnosis and shortly thereafter discontinued such intervention, two other individuals (Units 2 & 5) had never consulted a rehabilitative therapist at all. These findings were noted despite the literature which states that individuals with MND should receive multi-professional intervention on a regular basis (Gelinas, 1997; Kazandjian, 1997). With regard to non-medical or alternative interventions, two persons with MND (Units 2 & 3) were undergoing such treatments, with one person (Unit 4) having abandoned homeopathy and stem cell therapy. The alternative interventions that persons with MND referred to included reflexology, Reiki healing, homeopathy, stem cell therapy and “drug therapy”. In this instance stem cell therapy has been labelled as an alternative intervention because for the time being it is not recognised as a cure for MND or a means to arrest disease progression, and as yet it does not appear to form part of conventional management that is documented in the literature. In addition the treatment labelled “drug therapy” referred to a drip inserted twice weekly of unknown content. According to both the person with MND and her spouse (Unit 3), there is a centre in the Johannesburg region that claims that through the use of this “drug therapy” they are able to heal individuals with a variety of disorders, including MND and HIV/AIDS. However no additional information could be obtained on this treatment, and the participant who had taken part in this therapy also reported that at the outset of this intervention she was required to sign an indemnity form acknowledging her involvement in an experimental programme that could not guarantee a cure.

With regard to dysphagia only one participant (Unit 5) presented with no difficulties in this regard. All other persons with MND experienced problems of varying degrees of severity, with the majority of participants having to modify their dietary intake to

achieve improved feeding. Furthermore the person with MND from Unit 2 engaged in non-oral feeding through the use of a percutaneous endoscopic gastrostomy.

On the basis of participants' communication status as depicted in Table 3, it is evident that the degree of severity of the communication impairment was variable across participants. Two persons (Units 1 & 2) with MND were non-verbal and utilised no oral language. The participant from Unit 1 made use of an alphabet board in conjunction with eye gaze as a means of communication, while the individual from Unit 2 utilised a computer. Persons from Units 3, 4, and 6 used verbal communication, although speech was perceived as unintelligible and they relied on either written language or interpretations by their family members to facilitate conversation. Finally the participant from Unit 5 presented with intelligible speech in the presence of mild articulatory errors.

Given that persons with MND were required to present with a communication impairment on the basis of subjective opinions, following consent to participate in the study the researcher chose to verify these subjective reports through the use of objective means. The Frenchay Dysarthria Assessment (FDA) (Enderby, 1984) was thus used to assess formally the motor speech abilities of each person with MND, with the aim to quantify and ensure the presence of a communication impairment in the sample participants. The FDA was selected for use in this study based on the fact that it was efficient and easy to conduct, given the clear and systematic guidelines provided in the manual. According to Enderby (1984) ease of administration is important in that tests must be clear and practical to administer, so that therapists are not tempted to change procedures in order to reduce the time taken to administer the assessment. Also training for correct administration of the FDA was minimal, thus contributing to the reliability of the tool. Moreover the FDA is well standardised for describing and differentially diagnosing dysarthria, and has good test-retest reliability. In addition the FDA is not merely a checklist of the presence or absence of the various components of dysarthria, but also yields data that informs clinical practice and allows for quantitative comparisons to be made over time as well as across patients (Enderby, 1984).

The FDA comprises eleven sections including a) reflex, b) respiration, c) lips, d) jaw, e) palate, f) laryngeal, g) tongue, h) intelligibility, i) rate, j) sensation, and k)

associated factors. Each section is further divided into various subsections which can be viewed on the score sheet that is provided in Appendix A. The majority of these sections and subsections assess speech from the basis of anatomical and physiological functioning, while the section on associated factors aims to identify variables that may further influence communication (e.g. hearing) (Enderby, 1984). Administration and scoring of the FDA was done in accordance with the guidelines that are documented in the manual for this assessment battery. For further details regarding administration and scoring the reader is referred to Appendix B or alternatively the Frenchay Dysarthria Assessment manual (Enderby, 1984).

With regard to quantifying the communication impairment Table 4 depicts the participants' average scores across the entire FDA battery, where 1 represents no articulatory function and 9 represents normal functionality. Based on this table, statistical findings revealed that all persons with MND presented with some degree of speech impairment thereby confirming the subjective opinions of participants. Furthermore these findings agreed with the subjective impressions of communication evident in Table 3, where persons with MND who were non-verbal (Units 1 & 2) achieved the lowest score on the FDA, while the individual from Unit 5 who presented with intelligible speech attained the highest average score. A graphical representation of each individual's performance on the FDA is presented in Appendix C, along with the combined average scores of all participants for each subtest. Although a description of the features of each individual's communication impairment is beyond the scope of this discussion, because all participants did experience reduced function on almost every subtest of the FDA, the multi-system nature of dysarthria was highlighted (Love & Webb, 2001). Moreover, the fact that most participants presented with a variety of upper motor neuron signs (e.g. impaired rate and range of lingual function) and lower motor neuron signs (e.g. atrophy and fasciculations of the tongue) confirmed the presence of a mixed spastic-flaccid dysarthria, which is characteristic of the motor speech impairment associated with MND (Kent et al., 1992).



**Table 4: Participants' Average Scores Across the Entire FDA Battery**

<b>Unit Number of Person with MND</b>	<b>Average Per Participant (each subtest scored out of 9)</b>
1	3.00 (SD = 2.51)
2	2.50 (SD = 2.05)
3	4.57 (SD = 2.73)
4	4.11 (SD = 2.08)
5	7.68 (SD = 1.09)
6	3.64 (SD = 1.57)
<b>Average (Standard Deviation)</b>	<b>4.25 (SD = 1.84)</b>

Finally with regard to the associated factors that are depicted in Table 5, no significant variables were apparent that may have had a further influence on the speech impairment of each person with MND. Although it is possible that factors such as Menière's Disease, glaucoma and posture could have affected the communication of individuals, the researcher interpreted all findings in context and therefore did not believe that such variables were problematic in the individuals who participated in the present study. The reader is referred to Table 5 in order to obtain a further description and understanding of each person with MND.

**Table 5: Possible Influencing Factors for Each Person with MND**

<b>Unit No of Person with MND</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>
<b>Hearing</b>	NAR; adequate at a conversational level	NAR; adequate at a conversational level	NAR; adequate at a conversational level	NAR; adequate at a conversational level	NAR; adequate at a conversational level	NAR; Menière's Disease left ear; adequate at a conversational level
<b>Sight</b>	NAR; wears glasses for reading & watching television	Glaucoma; wears glasses for reading & watching television	NAR; wears glasses for reading & watching television	NAR; wears glasses for reading & watching television	NAR; wears glasses for reading & watching television	Reduced sight in right eye; wears glasses for reading & watching television
<b>Teeth</b>	Full set of dentures; teeth & gums appeared healthy	Full set of dentures; teeth & gums appeared healthy	Full set of dentures; teeth & gums appeared healthy	Own teeth in-situ; teeth & gums appeared healthy	Full set of dentures; teeth & gums appeared healthy	Full set of dentures; teeth & gums appeared healthy
<b>Language</b>	NAD based on conversational interactions; no additional testing required	NAD based on conversational interactions; no additional testing required	NAD based on conversational interactions; no additional testing required	NAD based on conversational interactions; no additional testing required	NAD based on conversational interactions; no additional testing required	NAD based on conversational interactions; no additional testing required
<b>Mood</b>	Very insightful; cooperative; motivated; very tearful	Very insightful; cooperative; motivated; resentful	Questionable insight; cooperative; motivated; very positive	Very insightful; cooperative; motivated; very positive; occasionally "down"	Questionable insight; cooperative; motivated; tearful	Insightful; cooperative; motivated; appeared "down"

<b>Unit No of Person with MND</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>
<b>Posture</b>	Sitting upright in wheelchair; slight asymmetry of chest & head; no obvious tension in shoulders; head control appeared adequate	Lying in bed; propped up by pillows; symmetry of chest & head; no obvious tension in shoulders; head control appeared adequate	Sitting upright in chair; symmetry of chest & head; no obvious tension in shoulders; head control appeared adequate	Sitting upright in wheelchair; slight asymmetry of chest & head; slight tension in shoulders; head drooping slightly to right side	Sitting upright in chair; symmetry of chest & head; no obvious tension in shoulders; head control appeared adequate	Sitting upright in chair; symmetry of chest & head; no obvious tension in shoulders; head control appeared adequate
<b>Rate (words / min)</b>	Not applicable – communicated via alphabet board & eye gaze	Not applicable – communicated via computer	Slow & laboured speech; less than 150 words per minute	Slow & laboured speech; less than 150 words per minute	Normal speech rate; 150 to 200 words per minute	Slow & laboured speech; less than 150 words per minute
<b>Sensation</b>	NAD for upper lip & tongue; overall sensation reportedly intact	NAD for upper lip & tongue; overall sensation reportedly intact	NAD for upper lip & tongue; overall sensation reportedly intact	NAD for upper lip & tongue; overall sensation reportedly intact	NAD for upper lip & tongue; overall sensation reportedly intact	NAD for upper lip & tongue; overall sensation reportedly intact

NAR = No abnormality reported

NAD = No abnormality detected

#### **2.3.4.2 Participatory Member of the Unit**

For each person with MND, one of his/her family members participated in the study (Table 3). The sample of participatory members of the Units comprised four females and one male, which included more specifically two daughters, one close female friend, one wife, and one husband. It should however be noted that for Unit 5 no family member, significant other individual, or individual trained as a carer participated in this study. Although the husband of the person with MND in Unit 5 had agreed verbally to participate in the research, he failed to arrive at the scheduled interview and instead informed the researcher that he no longer wished to be involved in the process. According to this individual's wife he had not yet accepted her diagnosis of MND, and perhaps perceived participation in the study to be too overwhelming. Although the participant inclusion criteria required the presence of a family member, significant other individual, or individual trained as a carer, the person with MND from Unit 5 was interviewed before her husband withdrew from the study. Furthermore upon examining the data that was provided by the person with MND, it was evident that very interesting information had been yielded, which the researcher believed would contribute to the value of this study. Moreover because this individual from Unit 5 was the only participant in the study who had been newly diagnosed with MND and presented with relatively intelligible speech, her inclusion contributed further to the diversity of sample participants. Apart from the advantages of sample diversity mentioned earlier, because case study research also allows for continuity and change in the dynamics of each study unit to be documented, and accommodates variation between cases (Grbich, 2003), inclusion of this individual was deemed appropriate. On this basis while acknowledging the importance of adhering rigidly to participant selection criteria in order to ensure the integrity of a study, the researcher in this case believed that the inclusion of Unit 5 was of benefit to this study in terms of the valuable information that the person with MND provided and the diversity that was added to the sample.

The average age of participatory members was 55.4 years ( $SD = 17.8$  years). All participatory members of the Units claimed to provide physical, emotional and financial support for the person with MND. In addition to these participatory members, Units 1, 3 and 4 also comprised formally trained carers who provided additional physical and emotional assistance to the persons with MND. The

individual from Unit 6 also relied on her husband in addition to her daughter for further support. Finally in terms of caregiver training and training to facilitate communication, no family members received input to this effect.

## **2.4 RESEARCH PROTOCOL**

### **2.4.1 Data Collection Procedure**

Data collection was conducted based on the following systematic procedure:

1. Ethical clearance was obtained from the Committee for Research on Human Subjects (Medical) and from the Faculty of Humanities at the University of the Witwatersrand, granting permission for the study to be conducted. A copy of the Research Clearance Certificate can be found in Appendix D.
2. Following ethical clearance a summary of the research proposal was submitted to the MND Association of South Africa and various neurologists, informing them of the study that the researcher wished to undertake. A letter of permission was submitted to each of these recruiting bodies requesting access to the contact details of persons with MND (an example of which is available in Appendix E). In addition various rehabilitation therapists who work in the field of adult neurogenic disorders were also contacted. In cases where such professionals were able to access persons with MND, a letter of permission as set out in Appendix E was either faxed or e-mailed to these HCPs.
3. In instances where the researcher's request for the contact details of persons with MND was approved, the various recruiting bodies contacted potential participants to inform them of the study and to gain provisional consent.
4. Once gaining provisional consent the researcher made telephonic contact with each person with MND. The availability of a family member who was able and willing to participate in the study was also established. In the event that the person with MND was unable to communicate telephonically, the researcher made contact with a family member and requested that he/she re-establish consent with the individual through non-verbal means.
5. Following verbal or non-verbal agreement by both parties to participate in the study, the researcher made an appointment to meet the person with MND and his/her family member.
6. Upon meeting the person with MND and his/her family member, the aim and protocol of the study was reviewed and the written information sheet was

provided (an example of which is evident in Appendix F). The aim of the information sheet was to communicate to both the person with MND and his/her family member a) the purpose of the study, b) a formal invite to participate, c) the basis for participant selection, d) the requirements of their involvement, and e) an assurance of confidentiality (Grbich, 2003). Both the person with MND and his/her family member were required to sign separate consent forms, agreeing formally to participate in the study (Appendix G). The principle of informed consent implies that participants are entitled to know their role in the study by understanding their purpose in the project, and the nature of the research instrumentation to be utilised. Such an understanding and willingness to participate reduces vulnerability and acts as a protective mechanism for participants (Grbich, 2003). In the event that the person with MND was unable to sign the consent form, consent was obtained verbally and the family member was required to sign on behalf of the person with MND.

7. Following consent the researcher conducted an interview with the person with MND and performed a motor speech evaluation. Thereafter an interview was also conducted with the family member. Both interviews were conducted separately, such that while the person with MND was participating in the interview his/her family member was not present, and vice versa.
8. On completion of the interviews and motor speech evaluation, for those persons with MND who had not been recruited by a neurologist, the researcher requested their permission to contact the diagnosing physician in order to confirm the presence of the disease. Although other recruiting bodies and members of each Unit were certain of the diagnosis, the researcher wished to obtain accurate details from a neurologist.
9. Upon contacting each person's neurologist, the researcher informed the professional that the person with MND had provided permission for information regarding his/her diagnosis to be divulged. The researcher requested medical details about the person with MND at the time of diagnosis.
10. On completion of the data collection process all participants were provided with a letter from the researcher, thanking them for participating in the study. In addition, participants with MND who were not receiving management from a speech-language pathologist were provided with the contact details of

various bodies that either offer the appropriate speech-language pathology services, or would assist the individual in making contact with an appropriate speech-language pathologist in his/her area (Appendix H).

#### **2.4.2 Data Collection Method**

The data collection method comprised two components, namely an interview with the person with MND and an interview with his/her family member.

##### **2.4.2.1 Interview with the Person with MND**

Persons with MND were interviewed by the researcher in their homes. The interviews were conducted alone in the absence of a family member, as the researcher wished to prevent responses being influenced between parties. Although interviews were envisaged to take approximately 60 minutes, the average interaction with a person with MND took approximately two hours in view of the severe communication impairment that was experienced by almost all participants.

Each interview followed a semi-structured format, whereby the researcher utilised a predetermined interview schedule to guide the interaction between herself and the person with MND. The interview schedule comprised various questions accompanied by a variety of appropriate probes, so as to elicit the necessary information that would address the research question. These probes were however not worded as specific questions, because the use of probes is aimed at providing a mere indication of the subtopics that the researcher wishes to explore in detail (Arthur & Nazroo, 2003). The probes on the present interview schedule were thus a guide to simply facilitate the interview process, and allowed for the inclusion of additional statements or probes based on what was deemed appropriate during each interaction with a particular participant (Arthur & Nazroo, 2003). As a result the researcher was consequently afforded a degree of control during the interview process in that she was able to ask specific questions while probing responses simultaneously to yield rich and in-depth information, as well as achieve a level of consistency between participants (Arthur & Nazroo, 2003; Drummond, 1996). Moreover allowances were also made for the interviewee to expand on any questions asked, or pursue different points of interest as they arose (Drummond, 1996).

In the event that the person with MND presented with minimal or absent verbal communication, the researcher modified the interview process in order to accommodate the interviewee's response mode. In cases where the person with MND utilised a form of alternate and augmentative communication, the interview was conducted via the available communication modality. However in situations of compromised verbal communication and no alternate or augmentative communication in-situ, the researcher implemented a means of communication that best suited the individual. For example in the presence of functional use of the hands, the person with MND was requested to use written language to facilitate his/her communicative attempts. Alternatively head nodding or eye blinking was introduced if reduced motor ability prevented the use of the written modality or any other form of alternate and augmentative communication. Furthermore in such instances the researcher also modified questions and probes in such a way so as to elicit closed-ended responses, particularly of a yes-no nature. It is acknowledged that by reducing the interview to a single-word response format, the richness of data was undoubtedly compromised and the researcher was offered an opportunity to bias participants' responses either consciously or unconsciously. However, the reality of the situation is that such forms of communication are often the only means of interacting with individuals who are communicatively impaired.

Prior to the commencement of each interview, the researcher spent time with the person with MND familiarising him/her with the communication mode that would be utilised in an attempt to achieve successful and reliable communicative interactions. All participants were requested to provide as much information and detail as they felt comfortable. During the course of each interview, participants' responses were recorded on the interview schedule below each question and the accompanying probes. Any additional information that was yielded and deemed relevant to the study was noted in the space provided on the interview schedule.

#### **2.4.2.2 Interview with the Family Member**

Unlike the interview with the person with MND that aimed to determine his/her specific perceptions regarding management practice for this condition, the interview with family members aimed to establish their personal perceptions concerning both the medical and rehabilitative management of the disease. In addition the interview



with the family members also provided a means of verifying certain factual responses (e.g. time of diagnosis) obtained from the person with MND.

The interview with the family member took place at the home of the person with MND and took approximately 60 minutes to complete. Interviews were conducted in the absence of the person with MND so as to prevent family members from feeling pressurised to provide responses that would be acceptable or desirable to the individual with this disease. The same semi-structured interview format and interview schedule was utilised, as described for the interview with the person with MND. Questions and probes were however worded to elicit the perceptions of the family member, and not what he/she thought the person with MND might have perceived. Participants' responses and additional information rendered were again recorded on the interview schedule in the spaces provided. Family members were also encouraged to provide as much information and detail as they felt comfortable.

It is important to note that although the literature reports the benefits of tape recording interviews so as to allow the interviewer sufficient time to respond appropriately to the needs and cues of the interviewee (Legard, Keegan & Ward, 2003; Patton, 1987), neither the interviews with persons with MND or the interviews with their family members were tape recorded in the present study. During the interview with the person with MND, tape recording was not practical given that the majority of individuals were either non-verbal or had limited speech intelligibility. Also given that participants responded very slowly and exhibited reduced sentence complexity, the researcher had sufficient opportunity to record all responses provided by the interviewees. In addition where persons with MND had used written language to respond to questions, the researcher kept these response sheets and therefore had recordings of verbatim responses. With regard to the interviews with family members, tape recordings were also omitted from the data collection method in order to achieve consistency in the methodology. Since the subtleties of communication (e.g. intonation and pause) can have a significant effect on data interpretation (Legard et al., 2003), by eliciting equal amounts of data between persons with MND and family members, bias in the data interpretation phase was prevented. Furthermore since semi-structured interviews run the risk of eliciting vast amounts of unnecessary

detail (Arthur & Nazroo, 2003), the absence of tape recording allowed the researcher to record only that which was deemed salient to the study.

## **2.5 RESEARCH INSTRUMENTATION**

The research instrument that was utilised to elicit the perceptions of persons with MND and the perceptions of their family members with regard to MND management was that of the interview schedule.

### **2.5.1 Rationale for a Combined Face-to-Face Interview with Guiding Interview Schedule**

In conjunction with the interview schedule, the data collection process took the form of face-to-face interviews. Such interviews minimise the possibility of missing data and facilitate the establishment of rapport, which reportedly improves the interviewee's willingness to co-operate in a study (Peat, 2002). A combination of an interview and guiding schedule is thus described as a beneficial means of data collection because a schedule allows one to focus and contain the interview, while the researcher also has the opportunity to explain to participants any ambiguous questions that may emerge and clarify participants' answers in response to certain questions. An interview is therefore a means for validating the interview schedule (Gorden, 1969; Phillips, 1971). Moreover in the present study it was important for the researcher to assist in the interview process, because although patients are said to be apt in reporting their feelings, they often cannot comment on with sufficient detail the communicative behaviours of HCPs (Epstein, 2000). It was thus necessary in this study for the researcher to facilitate the interview so as to ensure that the participants did not merely "vent" or provide their emotions about management practice in MND, but rather highlight different behaviours of HCPs that engendered such feelings. To this end Berg (1995) states that an interview schedule is therefore an effective method for exploring any particular area in depth, as well as gaining an understanding of the perceptions of participants with regard to a particular topic and how they attach meaning to the phenomenon in question.

### **2.5.2 Construction of the Interview Schedule**

According to Fossum and Arborelius (2004) it is essential that one studies the communication behaviours between patient and HCP, because factors such as patient satisfaction, patient compliance, patient understanding, treatment outcomes and

efficacy, and thus the patient's overall perceptions of his/her healthcare encounter, are founded upon patient-professional communicative interactions. The researcher therefore believed in the present study that if participants were questioned about communicative interactions between themselves and their HCPs, then perceptions regarding patient-centred care, patient-centred communication, and bioethical practice would be elicited, thereby giving rise to their overall perceptions relating to the medical and rehabilitative management of MND. In saying this however, although there are a variety of measures available to assess the communication that arises in healthcare (i.e. health communication), there is presently no gold standard for measuring patient-centred communication (Zandbelt, Smets, Oort & de Haes, 2005). Moreover there are no instruments available that facilitate the exploration of communication behaviours between the patient and the professional in the presence of the patient being communicatively impaired, as in the case of individuals with MND. Thus in view of the failure to locate a research instrument that was sensitive to the current study, the researcher developed an original tool to elicit the data required.

In order to construct the interview schedule a review of the relevant literature was conducted (Berg, 1995), so as to ensure that the content of the research instrument was appropriate and suitable to meeting the aim and sub-aim of this study. Additional information and insight beneficial for constructing the interview schedule was also obtained through a preliminary interview phase. Individuals with experience in the field of MND, such as a speech-language pathologist and a medical HCP were interviewed, as well as persons and their family members who had been exposed to various health conditions that require ongoing medical and rehabilitative management. Although it is acknowledged that interviewing individuals with MND and their family members would have been more appropriate for aiding the development of the interview schedule, the researcher had difficulty in recruiting sufficient numbers of persons with MND for both the preliminary interview phase of the study and the actual data collection stage. On this basis an individual with Parkinson's disease and his wife were consulted, as this disorder is also a neurodegenerative condition and is in many ways similar to MND as it too requires ongoing medical and rehabilitative management. In addition an individual who had suffered a severe gunshot wound to the face, and his wife were also interviewed. This dyad provided beneficial information during the preliminary interview phase, as the

victim and his wife had been involved in years of ongoing management with a variety of medical, allied medical and alternative professionals, and he had been required to make many important decisions regarding his future.

The preliminary interview phase comprised separate face-to-face interviews with the persons mentioned in the paragraph above. The goal of each interview was to yield information that would assist the researcher with the development of an instrument suitable for addressing the aims of the current study. For example when interviewing the professionals, questions were asked with regard to their opinions on current management practice for MND, whether or not the communication impairment was perceived to impact on management, whether changes needed to be made in terms of the way in which professionals communicate with persons with MND, and whether they felt that current management for MND is patient-centred and bioethical. For the Parkinson's disease and gunshot wound dyads, questions related specifically to the communicative interactions experienced between professionals and the patient, and between professionals and the family members. Questions therefore addressed issues such as communication preferences, for example whether the HCPs should communicate with the patient, with the family member, or with both individuals. The communication style of HCPs was also investigated, and focused on aspects such as maintaining or avoiding eye contact, and the use of jargon during communicative interactions. In addition dyads were questioned regarding patient-centred and bioethical behaviours that are conveyed through communication. For example questions were asked about disclosing or withholding information, and the amount of autonomy and power given with regard to decisions pertaining to management. Finally dyads were also requested to provide any additional information or experiences that they had endured and felt would assist the researcher in any way.

Prior to conducting all preliminary interviews, preparation was done in terms of the probes that would be used by the researcher to guide the discussion, so as to elicit the underlying issues, opinions, attitudes and experiences pertinent to the research topic in question. Questions posed by the researcher were open-ended in nature, offering participants maximum opportunity to convey their thoughts and ideas in detail. All information provided by participants was recorded by the researcher for possible use when developing the research instrument (Frey & Fontana, 1993). Based on the

information provided from the literature review and the preliminary interviews, the researcher then developed a research instrument (i.e. an interview schedule) entitled “The Communication Taxonomy of Perceptions Regarding the Medical and Rehabilitative Management of Motor Neuron Disease” (Appendix I).

### **2.5.3 Types of Questions**

“The Communication Taxonomy of Perceptions Regarding the Medical and Rehabilitative Management of Motor Neuron Disease” comprised mainly open-ended questions, with the inclusion of some closed-ended questions. A combination of both question types was used because effective in-depth interviewing includes a mixture of both broad and narrow questions (Legard et al., 2003).

In terms of the open-ended questions, both descriptive and probing questions were predominately utilised. Descriptive questions elicit a wealth of information from the interviewee about a topic that he/she knows well. They are also used early in the interview process when the interviewer begins with broad questions (Grbich, 2003). In terms of the current study many general descriptive questions were posed throughout the entire interview. For example such questions included, “*How did you feel after the diagnosis?*” or “*What recommendations were given to you?*” A further descriptive technique that was used by the researcher was the rendering of polar positions to discover the interviewee’s stance on a controversial issue (Grbich, 2003). For example a question might have been posed such as, “*Some individuals with MND said that the support group offers much assistance, care and information, while others said that the group is completely useless and of no value. What are your views on this issue?*” Although this technique requires the researcher to divulge information given by another interviewee, a preliminary exposé of already gained knowledge is essential if confirmation of certain issues is to occur. Furthermore this type of questioning focuses the interviewee on very specific issues that he/she might have not considered previously, while also opening the discussion to certain topics that the respondent may have felt uncomfortable or vulnerable discussing (Grbich, 2003). In addition to descriptive questions, the researcher utilised probing questions to narrow the broad information provided throughout the interview. Probing techniques included the use of silence, facial expressions and verbal cues such as, “*oh*”, “*really*”, “*well*”, and “*so let me get this straight, first this..., then this..., and now this*”. The aim of these

probing questions was to highlight to the interviewee that although the information that he/she had provided was valued and far greater than the interviewer's knowledge, a discrepancy had been noted. Thus the probing techniques helped to ensure that the researcher was a "critical friend" rather than merely a credulous recipient of any story (Grbich, 2003). Another open-ended questioning technique that was employed in this study was the use of hypothetical questions. One hypothetical question adopted by the researcher was, "*If a support group was established for MND that met on a weekly basis to provide education and rehabilitation, do you think this would make a difference to you?*" Such questioning poses an ideal or confronts the interviewee, thus probing his/her opinions and provoking further discussion (Grbich, 2003). A final technique that was used included summary questions to clarify and verify participants' responses. At the end of each section on the interview schedule the researcher provided a summary and integration of the information yielded, and asked the interviewee for confirmation or further explanation. This technique reportedly orders data and prevents it from becoming too difficult to handle (Grbich, 2003). Moreover summary questions also aimed to wind down the interview, as Arthur and Nazroo (2003) suggest that it is important that participants are given the opportunity to move away from any feelings of distress or anger for example that may have been generated during the discussion.

With regard to closed-ended questions, questioning of this nature occurred throughout the interview process although its use was limited in comparison to open-ended questions. Following each interview the researcher completed a self-evaluation to assess her interviewing techniques. On evaluation it was established that although several closed-ended questions were used such as, "*Have you ever attended physiotherapy?*" they were followed inevitably by an open-ended question such as, "*What are your opinions with regard to physiotherapy?*" Such questioning was done intuitively on the part of the researcher in order to yield maximum data, and therefore confirms the fact that closed-ended questions alone offer limited responses to individual contexts, and prevent the generation of in-depth information (Arthur & Nazroo, 2003). Furthermore in the medical encounter, Ford, Fallowfield and Lewis (1996 as cited in Zandbelt et al., 2005) state that closed-ended questions limit the range of patient responses and discourage information disclosure, as opposed to open-ended probing that gives patients space to respond. On this basis a combination of

both open-ended and closed-ended questions was used for the present study, deeming it particularly beneficial when little is known about the research topic in question (Peat, 2002).

#### **2.5.4 Content of the Interview Schedule**

“The Communication Taxonomy of Perceptions Regarding the Medical and Rehabilitative Management of Motor Neuron Disease” was designed to elicit participants’ experiences, attitudes, opinions, ideas and understanding of medical and rehabilitative interventions that are received on and following diagnosis of MND. The interview schedule therefore aimed to yield data that would inform the researcher about patient-centred care, patient-centred communication, and bioethical practice that is inherent to the overall management of MND. Furthermore since communication is a fundamental part of the management of any disease (Fossum & Arborelius, 2004), communication and the components comprising communication were used as a “vehicle” for eliciting data that would reveal participants’ perceptions. The principles and components that govern communication thus laid the foundation for the interview schedule upon which to question participants and provoke further discussion surrounding their journey relating to the management of MND.

The content of the interview schedule comprised four main sections and various subsections as set out in Table 6. The main sections included a) personal information, b) perception-based communication profile, c) concluding comments, and d) ethical behaviours. Each section was designed according to a funnelling sequence, whereby general questions were asked first followed by increasingly more specific ones. Such a format was adopted so that the interview would flow and interviewees would not feel pressurised at the outset of the interaction with the researcher (Arthur & Nazroo, 2003). The content and rationale for each section appears in the write-up that follows.

**Table 6: Content of the Communication Taxonomy of Perceptions Regarding the Medical and Rehabilitative Management of Motor Neuron Disease**

<b>Section</b>	<b>Heading</b>
Section A	Personal Information
Section B	Perception-Based Communication Profile
Subsection a	Communicative Style of the Professional
Subsection b	Communicative Content
Subsection c	Healthcare Consumer-Professional Relationship
Subsection d	The Person with MND as a Communicator
Section C	Concluding Comments
Section D	Ethical Behaviours
Subsection a	Bioethical Principles
Subsection b	Principles Relating to the Patient-Professional Relationship

**Section A: Personal Information**

According to Berg (1995) the initial questions asked in a questionnaire or interview should be easy straightforward questions that encourage full participation in the study. This first section of the current interview schedule therefore aimed to establish personal or case history information about the participant. Within this section of the interview schedule two separate components were developed, one to be completed when interviewing the person with MND, and the other for completion when interviewing the family member. The first component relevant to the person with MND was designed to elicit his/her biographical information. Questions for example pertained to diagnosis and symptoms, as well as participation in daily activities, members of the Unit, communication competency, and management or intervention history. The second component specific to the member of the Unit who participated in the study (i.e. a family member), addressed biographical details regarding the person with MND, so as to verify responses provided in the previous component by this individual. In addition questions were also asked about the family member's role in the Unit and his/her relationship with the person with MND, as well as training that might have been received to prepare himself/herself for caring for a terminally ill individual, and communicating with a communicatively impaired person. Such opening questions not only eased the respective interviewees into the study but also facilitated the development of rapport and trust between the interviewer and the



interviewee, which is essential for eliciting reliable responses as the research process progresses (Berg, 1995).

### **Section B: Perception-Based Communication Profile**

This section of the interview schedule elicited participants' perceptions with regard to the communicative interactions that occurred between persons with MND and treating HCPs. It aimed to establish a communication profile to depict the areas of communicative strengths and weaknesses, and communicative concerns and preferences that arose during interactions between persons with MND and their HCPs.

Reportedly health communication encompasses narratives around health, perceptions of health, medicine, and healthcare services and policies (Thiede, 2005). More specifically health communication focuses on specific tasks and observable professional behaviours such as interviewing, explaining, providing instructions and information, and offering counselling. In addition interpersonal skills are a further building block for good health communication (Duffy, Gordon, Whelan, Cole-Kelly & Frankel, 2004). However while such an explanation of health communication may seem sufficient at a glance, and indeed elements such as information-giving and counselling are vital components of any quality patient-professional interaction, it does not focus on the very essence of communication and fails to encompass the fundamental or core theoretical elements that comprise communication. Theoretically authors believe communication is the process of sending and receiving messages in order to transmit information between persons or groups (McLaughlin, 1998). Beyond this "mechanistic" process McLaughlin (1998) states that communication is also a social behaviour, where social interactions have the capacity to affect the actions of other people or groups of people, as well as influence their thoughts, ideas and decisions. Similarly, interactions between patients and HCPs also have the capacity to influence individual behaviours and affect health outcomes (Fossum & Arborelius, 2004). On this basis when devising Section B of the interview schedule in order to elicit participants' perceptions regarding communicative interactions, attention was given not only to the importance of health communication but also to the theoretical underpinnings of communication in general. In acknowledging health communication and the core elements of communication in general, Section B of the interview schedule was divided further into four subsections including a)

communicative style of the professional, b) communicative content, c) healthcare consumer-professional relationship, and d) the person with MND as a communicator.

### ***Subsection a - Communicative Style of the Professional***

The communicative style of professionals referred to the manner and techniques used by HCPs to interact or engage with patients. This style was evaluated by eliciting participants' perceptions regarding HCPs' behaviours and actions relating to various domains of communication. The subsection was therefore divided into five further components, including a) speech / paralinguistics, b) non-linguistics, c) language, d) meta-linguistics, and e) integration of subsection. These components were selected by virtue of the fact that communication is a multidimensional and multicomponent process that comprises more than speech and language alone (McLaughlin, 1998). Researchers such as Dore (1986 as cited in McLaughlin, 1998) and Skinner (1957 as cited in McLaughlin, 1998) claim that speakers do more than talk, and therefore making sounds, speaking words, and producing grammatical sentences does not imply that one is a competent communicator. Communicative competency only occurs when speakers are understood by their listeners and when they are able to influence effectively their listeners' behaviours. Thus the essence of communication goes beyond mere production, and includes effective management of all properties vital for meeting the speaker's overall goal, and thus effecting change in the listener's behaviour (McLaughlin, 1998).

A brief discussion of the five components that are listed in the previous paragraph follows below. Statements in italics represent an example of the content that was used to introduce each component to the participant. In addition examples of probes used to elicit information about each component are provided. While the probes are indicative of jargon common to speech-language pathologists, such terminology was simplified during the interviews to aid participants' understanding.

#### ➤ **Speech / Paralinguistics**

*The professional speaks in a clear and understandable manner*

Examples of probes: *articulation, vocal intensity, rate and flow*

Speech is the dynamic production of sounds to communicate meaning through the neuromuscular control of the vocal tract. However conveying meaning is not done

through words alone, but also through the manner in which they are produced. Paralinguistics therefore refers to the melodic components of speech production, such as stress and intonation, which modify the meaning of a delivered message (McLaughlin, 1998). For the purpose of the interview schedule, speech and paralinguistics were incorporated into one component, because participants from the preliminary interview phase of the study did not perceive these constructs as being impaired in treating HCPs.

➤ **Non- Linguistics**

*The professional facilitates verbal communication through non-verbal means*

Examples of probes: *eye contact, gesture, facial expressions and proxemics*

Non-verbal communication is provided through the use of non-linguistic cues such as body language and gesture, and accompanies the speaker's words to enhance the quality of verbal communication (McLaughlin, 1998). According to Burgoon, Buller and Woodall (1989 as cited in Gallagher, Hartung, Gerzina, Gregory & Merolla, 2005) non-verbal contributions are a central part of the content of health communication, and not only augment the spoken word but also make meaningful statements in their own right. The inclusion of non-linguistic cues when investigating patient-professional interactions is thus important, because the absence of non-verbal communication inhibits disclosure of psychosocial concerns and the professional's awareness of these concerns, as well as signals the lack of involvement of the practitioner in the interaction (Gallagher et al., 2005).

➤ **Language**

*The professional's manner of speaking and the content of what is said is easy to understand*

Examples of probes: *sentence complexity, jargon, turn-taking, repair, and information quality and quantity*

Language can be defined as a social behaviour, a learned behaviour, or a system of mental rules in which shared symbols or words are used to convey ideas or feelings. The main components of language include syntax, semantics and pragmatics (McLaughlin, 1998). For the purpose of this study the constructs of syntax and semantics were dealt with on a superficial level. This decision was made because

participants from the preliminary interview phase did not perceive syntax and semantics as areas of language having a major impact on communicative interactions, relative to the significant reports made with regard to the pragmatic behaviours of HCPs. More attention was therefore given to pragmatics or the use of language, as this aspect reportedly comes closest to the heart of communication and focuses on the speaker's achievement of a practical outcome through the use of language as a tool (McLaughlin, 1998). In addition to elements of pragmatics such as topic initiation, turn-taking and repair, discourse or the extended verbal exchange of information was also considered. Cooperation principles described by Grice (1975 as cited in McLaughlin, 1998), which are fundamental for effective conversation, were included as probes on the interview schedule. Examples of these probes included the appropriate quantity of information provided, adequate quality or truthfulness, relevant information on the topic, and the delivery of information in a manner that is clear and understandable.

#### ➤ **Meta-Linguistics**

*The professional thinks about what he/she says when transmitting messages*

Examples of probes: *awareness of communication breakdowns, makes modifications to suit the individual's needs, adjusts content appropriately (e.g. jargon), and directs conversation to person with MND and/or family member*

*The professional thinks about messages that are received*

Examples of probes: *probes further when limited information or single word responses are provided, accurate interpretation of incoming signals, and responds appropriately to incoming signals*

Meta-linguistics refers to the skills available that enable one to talk about language, analyse language, and focus not only on what is transmitted but also the manner in which the transmission is accomplished (Shames, Wiig & Secord, 1998). This component of the interview schedule therefore facilitated the researcher in trying to ascertain whether HCPs appeared to demonstrate a sense of self-awareness regarding the messages that they transmitted and received. Probes for this section were generated on the basis of experiences and perceptions provided by the Parkinson's disease dyad and the gunshot wound dyad, as well as reports from the literature that describe meta-linguistics (McLaughlin, 1998; Shames et al., 1998).

➤ **Integration of Subsection**

*Additional comments regarding the communicative style of the professional*

This component of the interview schedule did not comprise any predetermined probes. It simply provided the interviewer an opportunity to review and summarise the findings yielded by the participant, as well as verify any misunderstandings. In addition the interviewee was given a chance to provide any additional information deemed significant to the topic under discussion.

**Subsection b - Communicative Content**

This subsection of the interview schedule focused on the content of information exchanged between the treating HCP and the person with MND. Health information is important for patient-centred care and plays a key role in facilitating individuals to become autonomous within their own healthcare (Arora, 2003). However because the exchange of information from patient to professional or from professional to patient is not consumed automatically or processed homogeneously (Thiede, 2005), this subsection of the interview schedule looked at the content of information transmitted between the healthcare consumer and HCP, and the potential for communication or informational breakdowns. In addition the pragmatic prerequisites necessary for the consumption and utilisation of health information were also considered (Thiede, 2005). The components of this subsection of the interview schedule included a) transmitting information, b) receiving information, and c) integration of subsection.

➤ **Transmitting Information**

*The professional provides information about MND*

Examples of probes: *information on diagnosis and progression, reviews information, sufficient information for decision-making, and sense of “hidden information”*

*The professional provides information about management in general and the future*

Examples of probes: *recommends management, discusses implications, and discusses support groups and collaborative decision-making*

A large component of any consultation with a HCP usually comprises information exchange. Moreover patients usually view the HCP as the primary and most important source of information (Leopold, Cooper & Clancy, 1996). Ironically however, studies have reported limitations in practitioners' abilities to convey health

information (Arora, 2003; Leopold et al., 1996; Tilden et al., 1995). Consequently patients often leave a consultation feeling confused and unsure about aspects of their health and/or treatment (Arora, 2003). The probes provided in this component of the interview schedule therefore aimed to establish the quality and quantity of information provided about MND, looking specifically at the type of information rendered and the participants' perceptions about its usefulness. The detail and adequacy of information with regard to the management of MND was also probed, as well as information surrounding long-term considerations and decisions. Given that the literature reports that professionals sometimes overestimate the understanding of information delivered to patients in oncology (Arora, 2003), and the fact that a diagnosis of either cancer or MND is devastating for the person and family concerned (Arora, 2003; Kazandjian, 1997), this finding was extrapolated to the MND population and hence probes for this study focused on similar occurrences reported by individuals with cancer.

➤ **Receiving Information**

*The communicative behaviours of the professional acknowledge the needs of the person with MND and/or the family member*

Examples of probes: *clarifies information or re-explains information misunderstood, provides opportunity for questions, acknowledges individual opinions, provides a sense of confidentiality, and listens and acts on the decisions of the person with MND and/or the family member*

Receiving information from the patient is as important as giving information, because a clear understanding of the subjective experience of living with an illness is likely to result in a more comprehensive treatment plan that maximises the quality of life of the individual. In order to receive information, professionals should therefore listen actively and attentively to the patient's story without interruption (Arora, 2003). According to Arora (2003) the manner in which the professional does this is vital because when one listens to a patient attentively and sympathetically, using open-ended questions, focusing on and clarifying psychological aspects, and communicating empathy, greater quality discourse interactions result which are beneficial for both the patient and the professional. Probes in this component of the interview schedule thus looked at the manner in which professionals elicited,

received, and acted upon information from persons with MND and their family members, acknowledging that healthcare consumers have a need to be recognised as individual and unique human beings (Arora, 2003).

➤ **Integration of Subsection**

*Additional comments relating to communicative content*

The aim of this component was as per that discussed in the previous subsection.

***Subsection c – Healthcare Consumer-Professional Relationship***

In light of the uncertainties associated with many types of diseases and their related treatment options, patients require significant reassurance about the legitimacy of their concerns and reactions (Rose, 1990 as cited in Arora, 2003). This reassurance stems from a good patient-professional relationship and is characterised by compassion, care and respect. When patients are treated as a “person” and feel that the professional genuinely is interested and sensitive to his/her needs, successful information exchange and decision-making is said to occur (Arora, 2003). In order to acknowledge the healthcare consumer as a person, this subsection of the interview schedule was divided into the following components, a) person with MND, b) family member, and c) integration of subsection. Since the aim of these components was to discover the perceptions of the person with MND as well as those of his/her family member with regard to the quality of the healthcare consumer-professional relationship, many of the probes that were devised were based upon patient-centred care, patient-centred communication, and bioethical practice. The researcher chose to separate the person with MND and the family member into two independent components based on findings from the preliminary interview phase. Reportedly patients and family members from both dyads noted differences in the way in which professionals had treated the patient in comparison to his/her family members.

➤ **Person with MND**

*The communicative behaviours of the professional acknowledge the individual with MND as a person*

Examples of probes: *treated with compassion, respects individual’s decisions, sense of honesty and truthfulness, is warm, friendly and empathetic, and gives support*

The probes used in this component aimed to establish whether the person with MND perceived himself/herself, on the basis of various interactions with HCPs, as being treated like a unique and valued person. In addition to persons with MND having to respond to the probes pertaining to this component of the interview schedule, family members were also asked to provide their perceptions about the way in which the individual with MND had been treated by various professionals. Probes were generated on the basis of input provided during the preliminary interviews with the Parkinson's disease dyad and the gunshot wound dyad. These individuals drew on their personal experiences, and provided their preferences in terms of what they perceived contributed to quality healthcare consumer-professional relationships.

➤ **Family Member**

*The communicative behaviours of the professional acknowledge the family member as a person*

Examples of probes: *provides ease and reassurance, promotes well-being, treated with warmth, friendliness and empathy, and acknowledges the family member's involvement in the management process*

The aim of this component of the interview schedule was to determine whether family members perceived themselves as being treated like valued individuals within the management process. Family members were therefore required to provide their perceptions about the healthcare consumer-professional relationship between themselves and HCPs, while persons with MND were asked how they perceived HCPs had treated their family members. Probes were again generated by virtue of the findings and recommendations yielded from both dyads during the preliminary interview phase.

➤ **Integration of Subsection**

*Additional comments relating to the healthcare consumer-professional relationship*

Rationale is as per that discussed in the previous subsection.

***Subsection d - The Person with MND as a Communicator***

Since the manner in which patients communicate with professionals is essential to the healthcare process, and studies have indicated that patients in general are often ineffective in terms of their communicative attempts with professionals (Post, Cegala



& Miser, 2002), the inclusion of the perceptions regarding the person with MND as a communicator were deemed important. This subsection of the interview schedule therefore comprised three components and included a) transmitting information, b) receiving information, and c) integration of subsection. These components were determined in accordance with a broad definition of communication, being a process of sending and receiving messages in order to transmit information (McLaughlin, 1998; Shames et al., 1998).

➤ **Transmitting Information**

*The person with MND is able to transmit messages effectively*

Examples of probes: *speech, non-verbal communication, alternate / augmentative communication, topic initiation, topic repair, and willingness and honesty in transmitting opinions, preferences and concerns*

Regardless of the mode of communication utilised, this component of the interview schedule investigated the ability of the person with MND to transmit messages successfully. Thus the perceptions of persons with MND and their family members were elicited to establish the communicative competency of the individual with MND. Probes were generated by reports from participants in the preliminary interview phase about the ease and/or difficulty of transmitting messages as a healthcare consumer. Information was also obtained from the literature about patient communication in the healthcare setting (Post et al., 2002).

➤ **Receiving Information**

*The person with MND is able to receive messages and act upon them*

Examples of probes: *awareness of miscommunications, requests repair or clarification, listens and acknowledges information received, and asks questions for information that is difficult to understand*

The aim of this component was to investigate how persons with MND perceived themselves, or are perceived by their family members as a recipient of the information that is conveyed within the healthcare setting. Probes explored how persons with MND received information, and how this information was used and acted upon. As in the previous component, probes were generated by reports from participants in the

preliminary interview phase, as well as from information obtained from the literature regarding patient communication in the healthcare arena.

➤ **Integration of Subsection**

*Additional comments relating to the person with MND as a communicator*

Rationale is as per that discussed in the previous subsection.

**Section C: Concluding Comments**

The final section of the interview schedule comprised five open-ended questions, requiring the interviewee to provide as much detail as possible for each question. The aim of these open-ended questions was to summarise briefly and draw conclusions from the interview, while offering the interviewee simultaneously a final opportunity to provide any additional information deemed relevant to the study. No specific probes were provided for this section because the nature of open-ended summary questions is such that no defined responses are required and the interviewee should be allowed to answer each question freely (Grbich, 2003).

The five open-ended questions follow below:

*Can you comment on whether you feel the management of MND is influenced by the communication impairment?*

*Do you feel that the professional's communication skills are representative of his/her interactions with all patients, regardless of the communication impairment?*

*Which members of the Unit do you feel are most effective in terms of their communication abilities?*

*What changes should persons with MND make to improve their communicative interactions with professionals?*

*What changes should professionals make to improve their communicative interactions with persons with MND and other members of the Unit?*

**Section D: Ethical Behaviours**

The purpose of this section of the interview was to investigate the perceived bioethical behaviours that arose during interactions between persons with MND and

their HCPs, or between family members and various HCPs. However unlike Sections A, B and C, Section D did not appear as an independent section on “The Communication Taxonomy of Perceptions Regarding the Medical and Rehabilitative Management of Motor Neuron Disease”. Rather this section was integrated within the other sections of the interview schedule. The researcher rejected the inclusion of an isolated section relating to bioethics based on the fact that communication and ethics are intimately related constructs, and one therefore cannot separate communication between a patient and a professional from the bioethical behaviours that are inherent to the patient-practitioner relationship. Moreover in order to abide by an ethical code of conduct, good communication on the part of the professional is essential (Gillon, 1985). On this basis bioethics was thus an integral part of the interview schedule. In theory Section D comprised two subsections and included a) the most commonly discussed principles of bioethics according to the literature, and b) the principles relating to the patient-professional relationship.

#### ***Subsection a - Bioethical Principles***

Moral decision-making in medical ethics is dependent upon the use of ethical principles. Although authors differ in terms of which principles are the most important, how such principles relate to one another, and which principles take precedence over others, the most commonly discussed principles in the literature include a) autonomy, b) beneficence, c) non-maleficence, and d) justice (Strand et al., 1998). The probes that were generated to address these various bioethical principles were based not only on a definition of each principle, but also on concerns and dissatisfaction, as well as positive experiences that arose during the interviews with the Parkinson’s disease dyad and the gunshot wound dyad.

##### **➤ Autonomy**

Examples of probes: *sufficient information for informed decision-making, collaborative decision-making within Unit, acknowledges individual’s opinions, and respects decisions made by person with MND*

Autonomy refers to the individual’s right to determine his/her own course of action, including decisions regarding medical care (Gillon, 1985). Moreover while respect for autonomy is fundamental to medical management, it is dependent upon adequate communication skills (Strand et al., 1998). In addition to reports provided during the

preliminary interview phase, the inclusion of autonomy was important in view of the possibility that although persons with MND have the cognitive capacity to make their own decisions, self-determination may be compromised based on limited communicative abilities.

➤ **Beneficence**

Examples of probes: *treated with warmth, compassion and empathy, offers reassurance and encouragement, delivers information in a tactful manner, and promotes well-being*

Beneficence is the act of doing good for an individual by being kind and merciful, and facilitating health and well-being. In its simplest form it is any action that will result in benefiting another person (Strand et al., 1998). Although autonomy and beneficence are often in conflict at the root of bioethics, and that performing actions which are beneficial may place an individual's independence at risk (Strand et al., 1998), the principle of beneficence was included in the interview schedule because in a sense it follows on from autonomy. If a patient's right to self-determination is denied, then in certain instances the professional's opportunity for being kind and promoting well-being may also be compromised.

➤ **Non-Maleficence**

Examples of probes: *feeling of being harmed, feeling of being damaged, physical versus emotional harm, and intentional harm*

Non-maleficence or preventing a patient from harm, involves the avoidance of both intentional harm and the risk of harm (Strand, 2003). This principle was included in the interview schedule because some researchers state that non-maleficence is the most important rule according to which HCPs should practise, and it has the capacity to override all other principles (Gillon, 1985).

➤ **Justice**

Examples of probes: *makes self available, gives time of day, and waiting times / ability to get an appointment*

From a medical standpoint justice usually refers to the distribution of services, and focuses on factors such as limited resources and the amount of time available to

dedicate to each patient (Strand, 2003). In the South African context where resources are limited and healthcare is not accessible to all citizens (Ross & Deverell, 2004c), the significance of incorporating this ethical principle could not be denied.

***Subsection b - Principles Relating to the Patient-Professional Relationship***

According to Strand (2003) the three most important principles relating to the patient-professional relationship include a) veracity, b) fidelity, and c) confidentiality. Overlap is said to exist between these principles on both a practical level and a principle level. As in the case of the bioethical principles, probes were generated in accordance with definitions documented in the literature (Gillon, 1985; Strand, 2003; Strand et al., 1998), as well as input provided during the preliminary interview phase.

➤ **Veracity**

Examples of probes: *sense of “hidden information”, sense of being told the truth, sense of honesty in the relationship, and truthful and honest about own concerns regarding health*

The principle of veracity relates to a professional’s obligation to tell the truth and refrain from deception (Strand, 2003). Professionals are therefore obliged to be honest in their relationship with a patient, and patients are expected to be truthful and honest about their own concerns regarding their health and mental status (Strand et al., 1998). Since patients and their spouses in the preliminary interview phase felt that they were not always informed fully about the presenting medical condition and the future, the principle of veracity was included in the current interview schedule.

➤ **Fidelity**

Examples of probes: *sense of lies and broken promises*

In addition to telling the truth, professionals are obliged to keep promises or agreements inherent to the relationship with a patient. Keeping promises includes the professional’s responsibility to be truthful and not deceive the patient, as well as an obligation to be beneficent by not causing harm, and maintaining confidentiality (Strand, 2003; Strand et al., 1998). Given the overlap that exists between veracity and fidelity, a comprehensive understanding of the patient-professional relationship relies on adequate knowledge of both principles, and hence the importance of including both constructs in the interview schedule is apparent.

### ➤ Confidentiality

Examples of probes: *sense of confidentiality or privacy within the relationship*

The principle of confidentiality holds the professional from disclosing any information entrusted to him/her regarding a patient. It is therefore an essential principle necessary for preserving fidelity (Strand, 2003; Strand et al., 1998). On the basis of the overlap that thus exists between the principles of veracity, fidelity and confidentiality, the inclusion of the latter principle in the interview schedule was indicated. Furthermore confidentiality is considered of grave importance in the healthcare arena, because it is essential for a sound healthcare consumer-professional relationship that is based upon trust and honesty (Strand et al., 1998).

## 2.6 PILOT STUDY

Prior to engaging in the formal data collection phase of this study, a pilot study was conducted. Pilot studies are of particular benefit when no previous research in a given field exists, as the researcher is provided with an opportunity to determine in advance whether the proposed plan will result in the data required in order to answer the research question. Based on these findings problematic aspects of the research design can then be modified, prior to commencing data collection for the planned study (Doehring, 1996; Pannbacker & Middleton, 1994). The aim of the pilot study in the current project was to identify potential problems with the research protocol, and demonstrate the appropriateness and feasibility of the overall research design (Drummond, 1996). Feasibility studies ensure that practical problems with regard to the research design and protocol are identified and dealt with, so as to facilitate accessibility to high quality data during formal data collection (Berzon, 1998; Peat, 2002). In addition, pre-testing of the interview schedule is recommended because it allows the researcher to modify questions that may be worded poorly, change items that expose the researcher's bias, and replace words which are emotionally laden (Baker, 1988). Finally pre-testing also aids in the success of the interview schedule with regard to obtaining information that is relevant to the study (Berg, 1989).

Following development of "The Communication Taxonomy of Perceptions Regarding the Medical and Rehabilitative Management of Motor Neuron Disease", a single case study was performed for the purpose of the pilot study. The single case study comprised a 71 year-old female with MND and her 38 year-old son. The full data

collection protocol as described under “Data Collection Procedure” and “Data Collection Method” was undertaken, including both the FDA and the interviews. The FDA was conducted to determine whether it was an effective tool for assessing motor speech competency in the sample population, and it provided the researcher with an opportunity to refine her skills with regard to the administration and scoring of this assessment battery. Thereafter the interview schedule was administered to the person with MND and her son individually, in order to ascertain whether the content of the tool was sensitive to the aims of the study, and to establish whether the predetermined questions and probes were worded appropriately and were not ambiguous or misleading. On completion of both interviews participants were required to identify any ambiguous or difficult questions that they could remember, as well as comment on the researcher’s interviewing style, and provide any suggestions or recommendations felt to enhance the data collection process or the study as a whole. In addition to suggestions made by participants, an independent observer was present throughout the entire pilot study. The independent observer ensured that the questions asked and the manner in which the researcher asked the questions was not ambiguous, and did not lead the interviewee into providing desired responses. The manner in which the researcher recorded responses was also evaluated by the observer, so as to ensure that the researcher was able to note responses accurately while still engaging with the participant and maintaining adequate eye contact.

On completion of the pilot study the researcher examined the findings obtained to determine whether the questions and probes utilised gave an adequate range of responses, and provided sufficient data to meet the main aim and sub-aim of this study. Feedback provided by the participants and the independent observer was also considered, and based on these comments, modifications and refinements were made to various aspects of the data collection process and the interview schedule (Peat, 2002). On the basis of the findings from the pilot study the following changes were made:

- The initial research protocol included a telephonic interview with medical professionals, allied medical professionals, and alternative professionals who comprised each participant’s Unit. The proposed aim of these interviews was to establish the perceptions of HCPs with regard to the medical and

rehabilitative management of MND. However upon investigation for the pilot study it was established that most persons with MND were not consulting professionals on a regular basis, and thus this aspect of the protocol was not deemed feasible for inclusion in the present research undertaking.

- While conducting the interviews for the pilot study, the researcher noted that participants interpreted certain questions differently to what had been intended. Such questions were thus reworded for the planned phase of data collection. In addition the researcher's awareness was also heightened with regard to the use of leading questions. Because in-depth interviewing aims to yield detailed information, interviewers are at risk for asking questions that may suggest a possible answer (Legard et al., 2003). On this basis the researcher therefore made every attempt to avoid the use of questions that may have guided the participant towards a desired response. For example rather than the researcher saying, "*That could not have been very nice?*" the question was reworded as, "*How did that make you feel?*" thus allowing the interviewee to provide any response that he/she felt was appropriate (Legard et al., 2003).
- Unlike the pilot interviews that followed the interview schedule rigidly, the formal interviews for the purpose of this study were conducted with greater flexibility. The researcher established that perhaps due to the emotional nature of MND, participants were eager to "tell their stories" without much probing from the researcher. Thus participants were offered an opportunity for detailed discussions regardless of the order that appeared on the interview schedule. According to Legard et al. (2003) flexibility in an interview is good, because it allows responses to be explored in full and offers the researcher a chance to be responsive to the issues that are raised spontaneously by the interviewee. Despite this flexibility however, the researcher did ensure that the specified questions and probes set out in the interview schedule were utilised throughout the interview, so as to focus the discussion and elicit the information necessary for answering the research question.
- A decision was made to administer the FDA after each person with MND had been interviewed, as opposed to at the outset of meeting the participant. By



conducting the interview first the researcher was able to establish rapport and build trust with the participant. This rapport was important so that when various tasks from the FDA had to be performed, some of which were perceived as invasive and/or embarrassing, the person with MND felt more comfortable performing them in front of the researcher.

## **2.7 RELIABILITY**

Reliability refers to the replicability of research findings and whether or not such findings would be obtained if the same or a similar methodology was to be repeated. Within the realm of qualitative research however, the extent to which findings can be replicated has been questioned (Lewis & Ritchie, 2003). Some qualitative writers have therefore coined reliability equivalent terminology and talk about the “confirmability” of findings, or the “trustworthiness” or the “dependability” of the data (Glasser & Strauss, 1967 as cited in Lewis & Ritchie, 2003; Hammersley, 1992 as cited in Lewis & Ritchie, 2003; Lincoln & Guba, 1985 as cited in Lewis & Ritchie, 2003). Regardless of the terminology that is used however, there needs to be some certainty that internal elements, dimensions, and factors of the original data set would recur outside the study population. In addition, since the reliability of findings depends on the likely recurrence of the original data and its manner of interpretation, consideration must also be given to the restrictions placed on the data by the researcher, and whether or not they have been employed consistently and rigorously (Lewis & Ritchie, 2003).

Within the present study several threats to the reliability or repeatability of the research findings were identified. Firstly given that the researcher conducted the interviews herself there was a risk of experimenter bias, whereby she may have lead participants into making responses that confirmed the hypothesis of the study, either through a conscious or unconscious thought process. Also modelling effects may have occurred where the interviewer modelled unconsciously a desired behaviour or response for participants to adopt (Drummond, 1996). Secondly, since reliability refers to the trustworthiness of research findings, it is also essential that the research instrumentation utilised in a study yield consistent results (Babbie & Mouton, 1998; Lewis & Ritchie, 2003). Given the novelty of the interview schedule used in the current study and its qualitative nature, the test reliability of the tool or its ability to

replicate data in future studies was not determined (Lewis & Ritchie, 2003). Thus it is uncertain whether the use of “The Communication Taxonomy of Perceptions Regarding the Medical and Rehabilitative Management of Motor Neuron Disease” would yield consistent results. On a practical level, by virtue of the emotional nature of MND and the fact that most of the interviews with participants were emotionally charged, it is possible that the data elicited may have been clouded by the strong feelings or emotions experienced by individuals. While it could be said that some participants used these interviews as an opportunity to vent their emotions, it must be acknowledged that it is the very experience and reality of such feelings that contribute to an individual’s perceptions, which is in fact the basis of this study. Hence the emotionality of this population was not seen as a significant enough factor to prevent the study from being undertaken. A fourth factor that may have compromised the reliability of this study was the fact that many of the questions posed to participants required them to rely on their memory of past events. It is therefore possible that some participants may not have remembered certain experiences or events with great accuracy and detail. In raising this concern however, when participants were asked by the interviewer to remember specific episodes or events, many of the respondents replied with the comment that a person does not easily forget such a life-changing and traumatic experience. On this basis the retrospective aspect of this design was not believed to place too great a threat on the reliability of the study. A final yet significant threat to the reliability of this study occurred in the interviews with persons with MND who were non-verbal and relied on a closed-ended response format. On numerous occasions the researcher feared that by modifying questions to a simple yes-no format, participants would be forced into providing one of two response options with minimal opportunity to explain or elaborate on their thoughts and ideas. In addition the researcher may have made her own interpretations about certain points of discussion, in view of the fact that participants were not able to offer their own explanations spontaneously. For this reason many of the probes on the interview schedule were repeated, to ensure that participants yielded the same or similar responses throughout the discussion. While the researcher thus made every effort to clarify and validate all responses provided by participants so as to avoid unreliable data due to assumption (Legard et al., 2003), there was nonetheless apprehension that words may have been placed into the mouths of participants unintentionally.

In view of the potential threats posed to the reliability of this research project, a variety of strategies were thus employed to either protect or enhance the study's trustworthiness or sturdiness. Firstly Lewis and Ritchie (2003) state that there is a need to assure the reader of the research process, and the reasons why certain protocols are adopted. To this end the researcher provided a very detailed chapter on the methodology adopted for this study. Every procedure that was undertaken was described in as much detail as possible, along with rationale and literature reports to enhance the quality and value of the information provided. In addition a detailed account of the data analysis process was also described (at the end of the chapter), documenting the steps that were taken to ensure comprehensive and objective analysis of the data (Lewis & Ritchie, 2003).

The second major precautionary measure suggested by Lewis and Ritchie (2003) is to obtain certainty that the research is robust, by conducting various internal checks on the quality of the data and its interpretation. The researcher therefore utilised several methods to safeguard the internal reliability of this study. Firstly all interviews that were undertaken were done so by the researcher. Although this condition may have resulted in experimenter bias and modelling effects already mentioned in this section, the reliability of a study is strengthened when an interviewer has a vested interest in what the participant has to say and is stimulated by the topic. Moreover in such instances the participant is better able to lay down his/her own thoughts, feelings, knowledge and experiences (Patton, 1987). Secondly in view of the emotional component of this study, the researcher gave all participants sufficient time to provide answers to questions, and elaborate on such responses. If a participant became emotional during the interview he/she was provided with time and support from the researcher, and was encouraged to think about his/her emotions and opinions, as well as take time to compose himself/herself before continuing with the interview. The researcher hoped that by providing participants with ample time they would be able to think about their thoughts and emotions as objectively as possible, before responding to any questions or probes. Thus by ensuring that fieldwork is conducted effectively and participants are given sufficient opportunity to portray their experiences, the reliability of a study is strengthened (Lewis & Ritchie, 2003). Finally with regard to the persons with MND who were non-verbal, the researcher made every effort to ask whether he/she had anything more to add after each close-ended response, regardless

of how difficult or time-consuming it may have been to elicit complex open-ended information. The importance of providing detailed information was reinforced to all participants, as well as the need for accuracy. Interviewees were therefore requested to indicate to the researcher if any miscommunications or misinterpretations of information occurred.

A further strategy that was employed to protect the reliability of this study was the use of two independent raters. The purpose of an independent rater is to strengthen a study's reliability by ensuring that judgements made by the researcher are in agreement with judgements made by an unbiased observer (Doehring, 1996). The first independent rater that participated in the study was a speech-language pathologist who has completed a Master's Dissertation. This individual was suitable for participation in the study given her knowledge of communication and her understanding of research. The researcher therefore believed that such grounding enabled this independent rater to evaluate the researcher's performance accurately, and thus make a valid contribution towards the overall reliability or trustworthiness of the study. Despite these qualities however, it is possible that this independent rater's knowledge may have posed as a form of bias by virtue of experiences and expectations that are perhaps inherent to speech-language pathologists and/or researchers. On this basis the second independent rater that participated in the study was a graduate from university, and knowledgeable of the research process, but not in any way familiar with either MND or the medical/allied medical professions. Furthermore the researcher chose to provide this individual with minimal information regarding the aims and hypotheses of the study, in an attempt to keep her involvement in the project as unbiased and impartial as possible.

Of the two independent raters only one was present per case study (i.e. the same independent rater was present for both the interview with the person with MND and the interview with the family member), and was selected at random. Prior to participation in the study the researcher familiarised each rater with the interview schedule and the FDA, informing her of the protocol that would be followed and what she was required to do during data collection. In the case of the rater who was inexperienced in the field of speech-language pathology, additional time was spent with her in order to explain in greater detail various terms and concepts used in the

interview schedule and the FDA. During each interview the independent rater was requested to observe the interactions between the researcher and the participant, and record the interviewee's responses and behaviours in as much detail as possible. The rater was also asked to record any other information that she felt was of value to the study. Immediately after each interview the researcher and the independent rater crosschecked and discussed the responses that were elicited by the participant. The aim of this crosscheck procedure was to ensure that the researcher's recording and understanding of the data was in agreement with that of the independent rater. In instances where the researcher and the independent rater were in disagreement further discussions were held to deal with possible misinterpretations. Every effort was made to resolve any disagreements and reach a reliable response outcome. The independent rater was also required to comment on the researcher's interviewing techniques, making her aware of any misleading behaviours or particular questions for example that were asked in an ambiguous fashion. Such awareness was aimed to prevent similar recurrences in the future.

An additional factor that was perceived to threaten the reliability of this study was related to data analysis, and the fact that qualitative data analyses are very subjective and at risk of being influenced by researcher bias (Spencer, Ritchie & O' Connor, 2003). Also the evaluation and interpretation of data that falls within the domain of ethics is very subjective and can be affected by personal attitudes and beliefs (Beauchamp & Childress, 1994). Given these potential threats and the fact that relative to more experienced researchers and ethicists, the researcher of this study had little experience in evaluating and interpreting data of an ethical nature, the need arose for additional measures to be employed that would further enhance the reliability of this study from the perspective of data analysis. Notwithstanding this need however, a paucity of literature is available that documents how data of an ethical nature can be safeguarded from subjective one-sided analyses. As a result the researcher introduced a novel dimension to the data analysis component of this study, in the form of a once-off focus group that was conducted after data collection and interpretation.

A focus group comprises a small number of people who possess certain characteristics and meet to provide their feelings and opinions about a given problem or experience (Frey & Fontana, 1993; Kevern & Webb, 2001). By virtue of the focus group

context, participants are able to present their own views as well as hear from other people, thereby offering them an opportunity to listen to and reflect on what is said. Focus group interviews therefore yield tacit, uncodified and experiential knowledge that can be used by social scientists to arrive at a better understanding of a social context (Frey & Fontana, 1993; Kevern & Webb, 2001). Moreover Morgan and Krueger (1993) state that it is important for the complexity of human behaviours to be discussed in relation to views elicited in group discussions, in order to avoid oversimplification and achieve a greater degree of complexity that more closely resembles human motivation. Consequently group interactions are thus a valuable means for generating different perspectives and gaining greater insights into complex and controversial topics (Finch & Lewis, 2003).

In the case of the present study individuals knowledgeable and experienced in the field of research and ethics were invited to participate in the focus group. In total the focus group comprised five individuals, including one medical doctor, one social worker, two speech-language pathologists and one audiologist. These individuals were asked to participate in the focus group based on the fact that they all had postgraduate training and experience in bioethics, as well as experience in postgraduate research. In addition one individual was also serving on the Committee for Research on Human Subjects at the University of the Witwatersrand, while another professional had previously been a member of an Ethics Committee.

The initial phase of the focus group revolved around the researcher informing participants about the study in terms of its aims, sample, methodology, and research protocol. Thereafter the researcher presented some of the raw data that was obtained during data collection, along with her interpretations of these findings. According to Spencer et al. (2003) it is important that researchers make the content of their qualitative analyses available to other individuals, in order that they might interrogate the data to enhance its trustworthiness. On completion of presenting the data a discussion between the focus group participants was provoked. All participants contributed to the discussion by providing their own opinions, perspectives, interpretations and potential solutions for resolving various ethical dilemmas. These perceptions were tape recorded to ensure that the content of the focus group discussion was accurate upon review. Finally by virtue of the participants' diverse

backgrounds and individual insights, the researcher was provided with a variety of different perspectives and opinions associated with the numerous issues that were debated. Such diversity thus contributed to the reliability or trustworthiness of the researcher's data interpretation, as well as provided a deeper understanding of the study's findings and its application within a broader context.

Notably the focus group was not part of the initial methodology and was only conceived of once the study was already underway. Consequently an additional letter had to be submitted to the Committee for Research on Human Subjects (Medical) stating the motivation behind the focus group, and requesting approval for it to be assimilated into the study's methodology. A copy of the additional clearance certificate can thus be found in Appendix J, followed by Appendices K, L and M which contain the information sheet for potential participants, the consent form for participation in the group, and the consent form for the tape recording of the group discussion respectively.

## **2.8 VALIDITY**

Traditionally validity refers to the "correctness" or "precision" of a research finding, and the extent to which the construct under investigation is measured and evaluated successfully (Lewis & Ritchie, 2003). There are two dimensions pertaining to validity. The first dimension of internal validity refers to whether or not the researcher investigates that which he/she claims to investigate. External validity on the other hand determines whether abstract constructs or postulates that are generated, refined or tested are applicable to the broader population or a broader context or setting (Grbich, 2003; Lewis & Ritchie, 2003; Silverman, 2000). As with the case of reliability there is contention with regard to whether terminology characteristic of quantitative research can and should apply to qualitative studies. Terms such as "correctness", "credibility", "plausibility" and "transferability" are thus believed to be more appropriate for naturalistic enquiries or qualitative studies which require in-depth investigation (Lewis & Ritchie, 2003).

Reportedly the primary validity question that should be asked in relation to internal validity is, "*Are we accurately reflecting the phenomena under study as perceived by the study population*" (Lewis & Ritchie, 2003:274). This question gives rise to a host of additional questions relating to the strength of the research methodology, and

highlights the need for continual interrogation of the various methods utilised in the study in order to achieve precision and credibility (Lewis & Ritchie, 2003). For example according to Lewis and Ritchie (2003), the sample frame should be questioned in relation to any known bias. Through the use of criterion sampling this sample was believed to be free of known bias, given that participants presented at different stages of MND progression, exhibited different degrees of severity in terms of the communication impairment, and were recruited from different sources. With regard to the capturing of the phenomena, Lewis and Ritchie (2003) state that one should question the quality of questions used to explore the views of participants. To this end the preliminary interview phase with patients and experienced professionals facilitated construction of the interview schedule, while the pilot study assisted in determining whether the schedule investigated that which it aimed to investigate. The face validity of the tool was therefore ensured because “*on the face of it*” an association appeared to exist between what participants in the interview were asked, and that which was intended to be investigated in the study (Berzon, 1998; Peat, 2002). Also the interview schedule appeared to have adequate content validity in that a wide range of questions and probes based on the literature and prior experiences of individuals, were used to elicit an adequate sample of the content domain (Pannbacker & Middleton, 1994).

A further question relating to internal validity revolves around data interpretation and the need for internal evidence to support accounts or explanations that are posed (Lewis & Ritchie, 2003). This internal evidence can be seen in chapter four where the results of the study are discussed. Every explanation or statement that is made is supported by rationale depicting how and why the researcher made the various claims that are documented. Furthermore Lewis and Ritchie (2003) also suggest that data be displayed in a way that is faithful to the original data set or depicts the original material that was yielded, and allows the reader to see the analytic constructions that occurred. On this basis the researcher has displayed as much of the raw data as possible, through the text provided in chapter three. Thereafter a detailed discussion in chapter four illustrates the analytic constructions that were used to transform the original data into various interpretations and conclusions.



External validity is considered an inherent part of generalising because it asks whether study findings are applicable to broader populations or contexts. In the midst of generalising it is therefore crucial that findings are corroborated by other sources and validated against other evidence (Lewis & Ritchie, 2003). Corroboration in the present study was performed via the use of the focus group. Participants from the focus group were required to either confirm or reject the researcher's interpretation and conclusions of findings, as well as provide alternate perspectives and greater depth to the data analysis. Part of the group discussion thus centred around whether the findings of the present study could be applied to other persons with MND in other contexts, and whether certain results are perhaps representative of other clinical populations besides MND. Finally data interpretation was also validated through the use of current literature, in an attempt to establish and consider current trends in MND management outside of the sample of participants. However even with such checks in place, Lewis and Ritchie (2003) state that all of these methods to secure a study's validity and reliability are limited. *"We can never know with certainty that an account is true because we have no independent and completely reliable access to reality. We must therefore judge validity on the basis of the adequacy of the evidence offered in support of the phenomena being described"* (Hammersley, 1992 as cited in Lewis & Ritchie, 2003:276). One way to thus ensure such adequacy is to provide very clear descriptions of both the research method and research findings (Lewis & Ritchie, 2003). A detailed description of the methodology has therefore been provided in this chapter, followed by detailed coverage of the results and the discussion reported in chapters three and four respectively. The provision of such "thick description" permits readers to verify for themselves that claims made by the researcher are valid, and allows for the consideration of whether transferability of findings to other settings is possible (Lewis & Ritchie, 2003).

## **2.9 ANALYSIS OF DATA**

Apart from the FDA that was analysed in a quantitative manner, all other data was analysed from the perspective of a qualitative paradigm. The purpose of a qualitative approach to data analysis was based on the fact that *"If humans are studied in a symbolically reduced, statistically aggregated fashion, there is danger that conclusions, although numerically correct, may fail to fit reality"* (Mills, 1959 as cited in Berg, 1989:58). The use of a qualitative approach thus opens the whole realm

of human experience as it lends itself to the study of human communication disorders, which cannot be investigated easily by quantitative methods (Doehring, 1996).

A matrix based analytic method was used for data analysis, because it facilitates rigorous and transparent data management. The analytic tool that was used was a thematic framework, which is a central component of a matrix based analytic methodology and assists in the organisation of data into key themes and concepts. This particular form of analysis follows an analytic hierarchy and comprises subsections of a) data management, b) descriptive accounts, and c) explanatory accounts (Ritchie, Spencer & O'Connor, 2003b; Spencer et al., 2003).

### **2.9.1 Subsection a - Data Management**

The first phase in managing the data was to establish themes under which the data could be labelled, sorted and compared (Spencer et al., 2003). Even before determining themes however, the researcher had to familiarise herself with the raw data. Familiarisation is a crucial foundation for solid data analysis, and the researcher should review the material looking for potential gaps or overemphasis in the data, as well as the diversity of circumstances and characteristics specific to each participant (Ritchie et al., 2003b). The researcher familiarised herself with the data until such time that she felt she understood participants' circumstances and characteristics, and was aware of any possible flaws in the data set. Following familiarisation, many recurring and general themes were identified and divided into those of a substantive nature (i.e. attitudes, motivations or views) and those of a methodological ilk (i.e. the general atmosphere of the interview) (Ritchie et al., 2003b; Spencer et al., 2003). Indexing then occurred where all main themes and their sub-ideas were listed (Spencer et al., 2003). At this stage of the data analysis process the researcher ensured that the general themes were described in terms similar to that of the language used in the raw data, as the words used by research participants have explanatory power for later analytical tasks (Ritchie et al., 2003b; Spencer et al., 2003). Having constructed this initial conceptual framework, labelling of the general themes then occurred. The aim of labelling is to show which theme or concept is being mentioned or referred to in a particular section of the data. Labelling involves reading each phrase, sentence or paragraph in detail, and deciding what it is about and which parts of the index apply (Ritchie et al., 2003b). Following this labelling process the general

themes were sorted so that material with similar content was located together (Ritchie et al., 2003b), thus allowing the researcher an opportunity to focus on each subject in turn, unpacking all the necessary detail that related to similar data. The researcher was also aware of the possible need to assign some of the data to multiple occasions. This awareness is important because two seemingly unrelated pieces of data may provide clues for later explanations. The final component to the data management phase was that of synthesising the original themes, not only to reduce the amount of data to a more manageable size but also to assist in depicting the essence of the data for later discussion (Ritchie et al., 2003b). This process required the researcher to work through the themes very systematically, ensuring that the “new” data set was documented coherently so that its essence could be understood without referral to the original material. While the data management phase was very laborious and time-consuming its importance could not be dismissed, as the early stages of analysis are vital for the later phases that require in-depth interpretation (Ritchie et al., 2003b).

### **2.9.2 Subsection b - Descriptive Accounts**

Once the data had been managed, descriptive analysis began by studying the content and nature of each theme (Spencer et al., 2003). Detection was used whereby the researcher noted the range of perceptions, views and experiences within one theme across all cases (Ritchie et al., 2003b). On the basis of this range the researcher considered the key dimensions of the data and identified broader categories (Ritchie et al., 2003b; Spencer et al., 2003). Thus a process of categorisation occurred whereby descriptive data was assigned to broader categories. Thereafter a classification phase was entered where the researcher allocated the broader categories to new themes. Up until this particular stage of data analysis the descriptions used by the researcher had stayed close to the original text. However by assigning a description to each piece of data that had been placed in a newly classified theme, the analysis then moved beyond the original text and data interpretation entered a more conceptual level. Thus the new themes occupied a more abstract position and represented the final phase in ordering and describing the data (Ritchie et al., 2003b).

### **2.9.3 Subsection c - Explanatory Accounts**

Explanatory analysis of the data occurred following the classification of abstract themes. The aim of this section of data analysis was to establish possible

explanations for the study's findings, because an understanding of what influences various phenomena to occur is inherent to answering the research question (Spencer et al., 2003). In order to construct such explanations a number of strategies were employed. Firstly explicit reasons and accounts were adopted in some instances where participants were asked to describe how they felt or what they believed about a certain issue for example. Such explicit contributions are of immeasurable value in understanding the motivations and intentions behind human behaviour (Ritchie et al., 2003b; Spencer et al., 2003). However when participants were unable to convey overt factors relating to a specific situation or experience, the use of inference and underlying logic was then of value for establishing deeper explanations of phenomena. In some instances the researcher also made use of common sense to search for plausible explanations, although once these common sense explanatory accounts had been made explicit they had to be interrogated to ensure that their explanatory base was supported and reliable (Ritchie et al., 2003b). A fourth strategy that was used to generate explanations was based on the use of other researchers' empirical studies (Spencer et al., 2003). Sometimes researchers arrive at certain explanations and understandings by comparing the findings of their own study with those that have been carried out by others in the field. Thus when drawing from other empirical studies the researcher may "borrow" concepts or explanations to see how they might fit his/her own findings (Ritchie et al., 2003b). Finally Ritchie et al. (2003b) state that various explanations can also be based on particular bodies of literature or particular theoretical perspectives that are inherent to the discussion. Hence the researcher utilised various existing theoretical frameworks to explain patterns in the present study.

On completion of the explanatory accounts offered in relation to the present study's findings, the final tier of data analysis involved consideration of whether evidence from the study could be applied to a broader context (Ritchie et al., 2003b). The researcher thus considered whether findings of the present study had a wider application, albeit towards the development or extension of an existing theoretical framework, or the formulation or realignment of a social policy for example.

## 2.10 CONCLUSION

In conclusion, this chapter offers a detailed account of the methodology that was adopted for the present study. Although long and in-depth, the researcher believed it essential that readers are knowledgeable of the research protocol and underlying rationale utilised in the study, in order to understand the data analysis and how the overall conclusions were reached. After all Kvale (1996 as cited in White, Woodfield & Ritchie, 2003:289) notes, “*Qualitative research methods are often a ‘black box’ which needs to be opened up to the reader or user of the findings. Written accounts therefore need to explain not only how the research was conducted but also why particular approaches and methods were chosen to meet the aims of the research*”.

## **CHAPTER THREE**

### **RESULTS**

This chapter presents the qualitative findings from the interviews with all persons with MND and their family members.

A considerable challenge is posed in reporting the depth and richness of qualitative data. Unlike quantitative studies where the findings can be captured in a neat series of statistics, qualitative data reporting involves the ordering of disorderly data so that the reader can follow the “story” that is being unveiled (White et al., 2003). However not only is the ordering and management of qualitative data a challenge, but also reporting the findings in a manner that will satisfy the research objectives and enable the reader to understand them is equally difficult (Silverman, 2000; White et al., 2003). The key is therefore to report the data in a way that is both faithful to the original material and provides clarity about the interpretative process that was undertaken. The integrity of a study thus stems from the researcher’s ability to demonstrate that the discussion and conclusion that are presented have been generated from and grounded in the data acquired (White et al., 2003). Notwithstanding this importance is the temptation for qualitative researchers to include too much material, given the nature of qualitative data that is acquired (Silverman, 2000). Thus in order to manage the data of the present study so as to achieve a balance between the quality, accuracy and quantity of findings, this chapter has been divided into three sections and comprises a) participants’ perceptions, b) faithfulness to the original data set, and c) major themes.

#### **3.1 PARTICIPANTS’ PERCEPTIONS**

This section of the results chapter presents the participants’ perceptions of the medical and rehabilitative management of MND. The findings are reported in accordance with the order that is evident on the interview schedule. However the results have not been presented Unit by Unit because this process was conducted as part of the data management phase that occurred prior to the write-up of this study. Moreover the restrictions that were placed on this study in terms of length did not allow for an extensive presentation of all the research findings. Hence by presenting the results in a combined manner the researcher was provided with an opportunity to report the findings in a coherent fashion, and prevent excessive and overwhelming detail for the

reader (White et al., 2003). In addition this opportunity also allowed the researcher to provide firm evidence upon which the themes and discussion portrayed later in this study were generated. After all, the quality of qualitative research lies in the researcher's ability to move beyond the mere provision of ad hoc labels by providing clear proof and an analytical basis of the interpretative process (Silverman, 2000; White et al., 2003).

The results presented in this section do not include Section A (Personal Information) of the interview schedule, because such biographical details have been reported in the previous chapter. Furthermore little attention has been given to the frequency with which items occurred or the Units in which they occurred, because in qualitative research it is the content that contributes to the whole picture and not the frequency or percentage counts (Ritchie et al., 2003b).

### **Section B: Perception-Based Communication Profile**

#### ***Subsection a – Communicative Style of the Professional***

##### **➤ Speech / Paralinguistics**

*The professional speaks in a clear and understandable manner*

On the basis of communicative interactions with various HCPs, all persons with MND and their family members perceived the speech and paralinguistic components of the professionals' communication style to be appropriate. Factors such as articulation, vocal intensity, and speech intelligibility were thus viewed as clear and understandable, and any communication breakdowns that occurred between healthcare consumers and professionals were not perceived to be a result of defective speech and/or paralinguistic features.

##### **➤ Non-Linguistics**

*The professional facilitates verbal communication through non-verbal means*

All persons with MND and their family members perceived the non-linguistic style of professionals to be appropriate. Participants were confident that the HCPs' use of gesture and facial expressions for example was acceptable, and likely to have contributed to or facilitated communicative interactions between themselves and these individuals. Both participants from Unit 2 however commented on the use of eye contact by one particular professional, and the fact that throughout the entire

consultation he looked at his desk and failed to focus on them. This behaviour reportedly resulted in the person with MND feeling very uneasy throughout the entire healthcare encounter.

Although most of the participants were unable to comment on proxemics and body posture, three respondents were certain that had professionals behaved inappropriately in these domains they would have remembered any odd or remarkable behaviours. For the most part the non-verbal features of HCPs' communication skills were thus perceived to be intact.

### ➤ **Language**

*The professional's manner of speaking and the content of what is said is easy to understand*

With regard to the language used by HCPs, few participants perceived aspects such as sentence length and sentence complexity to be appropriate. For the majority of individuals the use of long complex sentences by professionals reportedly complicated their understanding of the disease and prevented them from assimilating all given facts pertaining to the nature of the condition. Such compromised understanding was highlighted by the person with MND from Unit 2. Despite this individual's medical knowledge and experience as a nursing sister, she stated that the manner or style in which the new and traumatic content was imparted to her, was not conducive to revealing a clear understanding of the disease. As a result, this particular individual questioned how other patients with no medical knowledge coped in a similar situation. In addition the use of jargon or medical terminology was perceived by more than half of the participants as affecting their understanding of MND. Thus by virtue of inappropriate sentence length and sentence complexity, and/or the use of jargon, content provided by professionals was perceived as being too complex to understand. Furthermore such complexity reportedly resulted in a variety of emotions such as confusion, anger, and anxiety. For two participants of this majority however, despite the difficulties experienced in trying to understand the communicative contributions made by various HCPs, these inadequacies were not perceived as problematic because the bottom-line or the final outcome of MND was still made clear to them. Hence this broader understanding was reportedly sufficient for both participants as highlighted by the husband in Unit 3 who stated, "*It was a*



*death sentence and nothing could be done, he needed not say anything more*". Finally the four participants who did not report any concerns regarding sentence length, sentence complexity, use of jargon, and/or complex explanations, informed the researcher that by virtue of their assertive personalities they had no qualms about asking the professionals questions. As a result when an issue arose that was unclear, the HCP was questioned immediately so as to alleviate any confusion or misunderstandings that may have been experienced. Moreover of these participants who did not perceive difficulties with the language used by HCPs, three were family members. On this basis although these family members did not perceive the language used by professionals to be entirely appropriate, they were more satisfied and accepting of such behaviours than the persons with MND.

When questioning participants about turn-taking, topic initiation, and repair, most persons with MND and their family members informed the researcher that they were unable to remember any remarkable instances that had occurred and were worthy of comment. In addition despite providing participants with various examples in order to facilitate elicitation of responses, several individuals suggested that no extraordinary behaviours had occurred that had captured their attention or appeared inappropriate. The person with MND from Unit 1 did however state that the one professional she had consulted had failed to engage in turn-taking behaviours. Reportedly this HCP was so hasty to convey information that there were no opportunities for either herself or her daughter to interject. Furthermore in terms of conversational repair, the same professional was perceived by the participant to be so disengaged from their communicative interactions that he appeared unaware of any breakdowns or miscommunications that might have occurred and warranted repair. As a result this participant stated that the distance between herself and the HCP had prevented a solid patient-professional relationship from being established.

Related to the language used by professionals, participants were questioned about the quality and quantity of information that was conveyed to them. All participants expressed dissatisfaction in this area and stated that a paucity of information had been provided by HCPs, and this had therefore impacted on their ability to cope with the disease. For example, three persons with MND stated that they were not informed at the time of diagnosis about the speech and swallowing difficulties that were likely to

arise. As a result of this lack of information the person from Unit 1 expressed her concern to the researcher about swallowing difficulties that she was experiencing at the time of the interview, and wondered whether she had an additional illness over and above that of the MND. All three of these individuals believed that had they been better informed about the nature of MND, they would have been better equipped to face the challenges inherent to this disease. In addition the majority of family members also stated that the limited input provided by HCPs lead them to feel anxious and fearful about adopting a caregiving role. Most of these individuals were unsure about what would be expected of them in the future, and they felt overwhelmed and unprepared knowing that a point would come when they would have to assist the person with MND with all activities of daily living. Furthermore as a result of this lack of information, at least one participant from each Unit acknowledged the importance of the Internet as a means of furthering their knowledge.

When participants were questioned as to why they believed the quality and quantity of information provided by professionals was so poor, a variety of suggestions were yielded. Firstly individuals from almost all Units believed that HCPs are simply not concerned about their patients, especially in view of the finality of MND. This idea was confirmed by the person with MND from Unit 1 when she stated that the poor quality and quantity of information was not so much related to the professional's poor communication abilities per sé, but rather related to his/her poor attitude. The idea of a poor attitude of the HCP was also encompassed in another statement made by the same person with MND from Unit 1 when she stated, "*They just can't be bothered, nobody takes the effort*". In addition there was also significant conviction that because HCPs believe that nothing can be done to assist individuals with MND, they see little reason to provide information and support because they know the patient's situation will not improve. The person with MND from Unit 2 highlighted this fact when she stated that the HCP sent her home knowing only that her diagnosis was a death sentence and nothing could be done to help her. Unit 3 reinforced this belief further when the husband reported that the professional whom they had consulted implied that he and his wife go home and get on with the job of living because, "*Nothing can be done for you*".

➤ **Meta-Linguistics**

*The professional thinks about what he/she says when transmitting messages*

*The professional thinks about messages that are received*

With regard to meta-linguistics, the first question that was probed by the researcher aimed to establish whether or not HCPs were perceived as demonstrating a sense of awareness in terms of their communicative contributions. Although most participants were unable to comment with certainty about the professionals' use of topic adherence for example, the person with MND from Unit 1 did state that a certain HCP whom she had consulted was very tangential. Reportedly this individual's output was disjointed and incoherent such that the participant's ability to make sense of any information provided was compromised severely. Conversely however, the same opinion was not elicited from this individual's daughter. According to the daughter from Unit 1, the difficulty in understanding the professional's communication lay not in following the topic of conversation but rather in understanding the jargon that was used. Furthermore, questions pertaining to perceptions of professionals' awareness of communication breakdowns and the need for repair revealed that there were many breakdowns in the interactions that participants either participated in or observed. However both persons with MND and their family members were uncertain as to whether this lack of conversational repair was a result of professionals being unaware of these breakdowns, or merely indifferent to the need and manner in which to attempt repair. Consequently of the participants with MND who experienced communication breakdowns, a sense of dejection and a feeling of being devalued as a communicative partner was reported.

Questions pertaining to the modifications or changes made by HCPs to facilitate the listener's understanding of communicative content, revealed the same responses for the majority of participants. There was agreement across all Units that HCPs made few attempts to ensure that participants understood the information that was conveyed to them. Reportedly most professionals imparted information in a once-off manner regardless of the time required by listeners to process the details. As a result of this haste many participants stated that they experienced difficulty in following and understanding the information that was provided to them. Contrary to this finding however, the husband from Unit 3 stated that a particular professional who he and his

wife had consulted did make an effort to complement his verbal explanations through the use of diagrams. While this effort was appreciated, the husband nevertheless reported that his understanding of the professional's communicative attempts was still compromised by virtue of the jargon that was utilised to explain the drawings. For the wife from this Unit however, she reported that the diagrams aided in her understanding of the disease irrespective of any jargon that the HCP had utilised. Moreover both participants from this Unit commented on the success of alternative professionals in terms of their communicative interactions. Reportedly the alternative professionals demonstrated an awareness and understanding of the needs of both the person with MND and her husband, explaining and re-explaining information until both parties understood. In addition the husband stated that the alternative professionals were also able to read non-verbal language, because if he or his wife appeared to misunderstand information or explanations that were rendered, clarification was then provided spontaneously.

Related to the needs of patients and their families, participants revealed that most HCPs directed conversation to the family member and failed to include the person with MND. As a result persons with MND reported feelings of isolation, exclusion, stupidity and frustration in not being a part of conversations regarding their own health. Although several family members expressed their understanding behind this exclusion in that it is simply easier and quicker for professionals to converse with a communicatively intact individual, they still experienced discomfort with this particular behaviour. While most family members also stated that they knew the person with MND very well and could probably speak on behalf of this individual, many believed that they were unaware of all the concerns and questions that the person with MND had relating to his/her health. General consensus between Units therefore highlighted participants' desires for communicative interactions to be directed to both the person with MND and his/her family member, given that the disease affects both individuals either directly or indirectly. In opposition to these findings however, the wife from Unit 4 reported that professionals should direct communication to the person with MND alone and exclude any family members, because it is this individual who is affected by the disease and has to bear the brunt of it. In addition to this comment, the wife of this particular Unit also stated on numerous occasions that she did not wish to learn about MND in its entirety, but

rather preferred to acquire information about the disease in small amounts as her husband's condition progressed. In this way she felt that she did not have to fear the future knowing the different challenges and obstacles that would arise.

The second meta-linguistic component that was investigated aimed to determine whether professionals appeared to demonstrate an awareness of the messages conveyed to them. The majority of participants stated that although HCPs were apt in acknowledging contributions made by family members, they were never aware of the needs and concerns of the person with MND. Moreover because of their communication difficulties, persons with MND were seldom given an opportunity to communicate their thoughts. In addition the majority of participants also reported that most HCPs were not willing to facilitate the communicative attempts of persons with MND, and were not patient in receiving incoming signals from these individuals. When questioning participants further about this finding, two main ideas were found to exist. Firstly many participants felt that professionals chose to avoid interactions with persons with MND, stating that HCPs do not know how to communicate with communicatively impaired individuals. Secondly participants also felt that HCPs are too busy to consult with one patient for more than the typical 10 to 15 minute appointment, and therefore cannot or will not afford a patient more time in the presence of slow and laboured speech, and/or a communication modality that relies on any other mode besides oral language. Hence participants felt that it is easier for professionals to direct communication simply to a family member, rather than spending the time that is required to interact with a communicatively impaired person.

In view of the perceived disengagement and lack of involvement by HCPs to communicate with persons with MND, all participants who stated that professionals failed to converse with them were consequently unable to comment on aspects such as the practitioner's awareness of communication breakdowns and his/her ability to request clarification. In general participants therefore reported that professionals were simply unaware of the communicative needs of persons with MND. For the few remaining participants who presumed that HCPs were aware of communication breakdowns and/or the need for repair for example, several participants once again suggested that had any overly bizarre or unacceptable communication behaviours

occurred on the part of the professional, they would have remembered such instances and been able to report on them.

Of the minority of Units who reported satisfaction with regard to the HCPs' abilities to facilitate communicative attempts and demonstrate patience in receiving incoming signals, the alternative professionals were again commended on their communication skills when interacting with persons with MND. Furthermore the participants from Unit 4 spoke very highly of the communicative abilities of the medical and allied medical professionals in Germany responsible for the stem cell therapy. According to both the husband and wife from this Unit, the HCPs in Germany were prepared to spend as much time as was necessary in order to not only elicit the thoughts and ideas of the person with MND, but also interpret these thoughts in an as accurate manner as possible. On this basis, the participants from Unit 4 reportedly found more value in the professionals and the treatment that they had received abroad.

Finally when questioning persons with MND and their family members regarding the professionals' interpretation and responsiveness to incoming signals, all participants perceived this area to be unproblematic. As stated by almost all participants, incoming signals were interpreted accurately because they were usually conveyed by a family member, and thus the HCPs did not have to cope with the challenge of decoding information that was produced by a communicatively impaired individual. However while this behaviour seemed to provide professionals with a way of understanding the person with MND, some participants did not find it entirely appropriate. As one individual with MND stated, "*He will never truly understand my concerns and experiences unless I am given the opportunity to express them myself*". Such desire to express one's own thoughts was highlighted further by the Units who consulted the alternative professionals and the HCPs practising in Germany. In both instances persons with MND were afforded the opportunity and time to communicate directly with these HCPs regardless of the time that such interactions required. As a result of these experiences both individuals expressed their satisfaction at being able to contribute to their own healthcare, as well as being acknowledged as a competent person despite the communication impairment.

➤ **Integration of Subsection**

*Additional comments regarding the communicative style of the professional*

In conclusion it would thus appear that although the communicative style of professionals did not seem to be affected by aspects such as speech, paralinguistics and non-linguistics, language and its components did have an impact on the interactions that occurred between patients and HCPs. The ability of persons with MND and their family members to understand the nature of the disease and its associated factors was affected by the complexity of language structures utilised by HCPs, as well as the over-use of medical terminology. Consequently the majority of participants perceived the quality and quantity of information provided by professionals to be inadequate. Related to this finding was the fact that the attitude of many professionals was one of hopelessness and a sense that because no assistance can be provided for persons with MND, individuals must live-out their time until death with minimal assistance. With regard to meta-linguistics most participants were unable to comment on the various questions posed by the researcher. Probes relating to communication breakdowns and conversational repair were difficult for participants to comment on because few professionals communicated directly with the person with MND. While the family members acknowledged the rationale behind HCPs directing conversation towards themselves and not the person with MND, individuals affected by the disease expressed negative emotions and a desire to be included in interactions regarding their life. Contrary to these negative experiences however, the communicative style of alternative professionals and/or professionals abroad was perceived in a more positive light. Not only did these HCPs reportedly offer persons with MND time to convey their messages, but they also facilitated communicative attempts and ensured that they understood the person with MND.

**Subsection b - Communicative Content**

➤ **Transmitting Information**

*The professional provides information about MND*

*The professional provides information about management in general and the future*

With regard to communicative content and the transmission of information, participants were questioned about the facts that were provided by HCPs in terms of MND, and whether they perceived their knowledge and understanding of these details

to be adequate. All persons with MND and their family members reported that the provision of information by professionals was entirely insufficient and had failed to prepare them for the challenges of coping with MND. Approximately half of the participants stated that although they understood the inevitable consequence of MND, they would have liked a simple explanation of what occurs in the body to result in the weakness that is experienced. As a result of this perceived lack of information, all Units reported to source their own information about the disease. Although a minority of participants reported some value in the provision of information from the MND Association of South Africa and Hospice, the significance of the Internet was common to each Unit. Despite this significance however, for some participants the Internet was also perceived as an additional source of stress. Given the multitude of sites that can be accessed on the worldwide web, individuals reportedly felt overwhelmed in deciding which would be the most valuable to read. In addition one person with MND also reported that many of the sites she had located were created abroad, and few were South African specific. This finding lead her to believe that little is known about the disease in South Africa, and perhaps HCPs are not as well equipped and as knowledgeable as their international counterparts. In addition to the Internet, participants from Unit 4 also acknowledged their experience in Germany as a significant source of information. Prior to leaving for Germany the wife reported that her and her husband knew very little about MND besides that which they had accessed on the Internet. However while receiving the stem cell therapy they were provided with a wealth of information such that when they returned to South Africa they felt better equipped to deal with the disease and its progression. Both participants thus expressed their appreciation for the opportunity to travel to Germany, stating that without this experience their ability to cope with the disease and support each other along the journey would have been severely compromised.

In view of the scant information provided by many professionals, participants thus felt that they were still unclear about the course of the disease and what to expect in the future. Although some individuals were told that their muscles would get weak and that they would eventually stop breathing, many participants were uninformed about specific functions that would cease. For example the person with MND from Unit 1 was unaware of the likelihood that swallowing difficulties would arise, while the individual from Unit 3 was unaware of the speech impairment that loomed.



Participants therefore reported that for a long while after the diagnosis, not only did they experience extreme hopelessness regarding the future, but also there was an overwhelming sense of inadequacy wondering how they would prepare themselves to cope with the disease. In addition, various family members who felt completely unprepared to function in the capacity of a caregiver also experienced inadequacy. Concerns were raised with regard to transfers from the wheelchair to the bath for example, as well as appropriate steps that should be taken in the event that the person with MND began to choke. Moreover of the participants from the six Units who did ask their professionals about future expectations and support systems, many were informed that nothing could be done to help them. This finding was highlighted by the comment made from the person with MND in Unit 3 where she stated, "*He was adamant that nothing could be done to help me*".

When discussing with participants the possible etiology of MND, all Units reported that their HCPs had informed them that no known causes of the disease could be specified. For many participants however the desire to explore plausible causes was highlighted to the researcher, and the possibility that knowledge of potential causal factors may have assisted some individuals in better understanding and accepting the disease. The benefit of understanding possible etiological factors was also apparent in Unit 4. While in Germany the person with MND was required to undergo a number of blood tests. The results of this testing revealed various heavy metals in the individual's system. Although unable to say with certainty, the HCPs in Germany suggested that these heavy metals may have been a possible factor associated with the onset of the disease. Furthermore this suggestion appeared to correlate with the fact that many of the heavy metals that were identified were used by this person with MND in the poisons on his farm. Thus on returning from Germany changes were made on the farm to eradicate the use of those poisons containing heavy metals. Although the person with MND acknowledged that such changes may have come too late or were possibly even unrelated to the MND, the fact that he was able to do something tangible provided him with a sense of being involved actively in his own health and well-being.

In view of the consistent reports by most participants that the information provided by professionals was insufficient, the researcher questioned individuals surrounding this

finding. Several participants stated for example that initially the amount of information provided to patients should be limited, because the overwhelming nature of MND does not allow for many facts to be processed and assimilated immediately. However while this rationale may hold firm, because HCPs failed to provide follow-up appointments there were no opportunities for participants to have information repeated, reviewed, or re-explained. Consequently the person with MND from Unit 1 stated, *“If you miss the information the first time then too bad”*. Also the participant from Unit 5 suggested that HCPs need to ensure that patients do in fact understand their diagnosis and its ramifications. Reportedly when this individual was diagnosed with MND, the professional put the responsibility on her by asking her whether she knew what the diagnosis meant. When given the label of MND she was reportedly shocked, as she assumed that the abbreviation “MND” used by the professional was the same as “MS” (i.e. Multiple Sclerosis). This assumption was perhaps made because she had a friend with Multiple Sclerosis and so automatically thought that the two conditions were the same. On this basis she therefore informed the HCP that she knew about the disease. It was only weeks later when she saw the written diagnosis in a magazine article did she realise that she had a different condition. Upon learning about MND in this manner the person with MND reportedly experienced significant fear and anxiety, and also questioned the accuracy of her diagnosis.

In relation to the provision of information, participants were asked whether they felt that the content provided had been sufficient to make decisions about their future. They were also asked to comment on whether they had experienced harm in any way, either physically or emotionally. In response to the first question the majority of participants reported that few if any decisions had to be made about the future because most professionals had said that nothing could be done to alleviate the situation. As a result more than half of the persons with MND believed that they had been harmed by virtue of a lack of information provision. For example following information provided by the researcher, the person from Unit 1 felt that had she been better informed about the swallowing difficulties associated with MND and the role of the speech-language pathologist in dysphagia, she could have taken more active steps to seek intervention in this regard. Notably however this participant did in fact attend speech-language pathology for a short period following diagnosis. Further to a paucity of information, several participants also perceived the way in which

information was delivered by professionals to be damaging. Reportedly most professionals were cold, tactless, unsympathetic and blatant about the prospect of death. The comment, "*She doesn't have much longer to live*" was damaging and overwhelming to both the person with MND and her daughter from Unit 1. Further devastation resulted from the statement made to the wife in Unit 4, when she was informed that her husband had two years left to live. At present both participants from Unit 4 regard this comment as particularly harmful, because the person with MND had at the time of data collection survived well over two years. These individuals therefore felt that professionals should not put a time limit on an individual's life, and suggested that HCPs rather be honest by saying that most persons live for up to two years, although some individuals do survive longer. In this way individuals are not only provided with the truth but are also offered a form of hope. An additional experience that was perceived as harmful by a minority of participants was the fact that they felt abandoned by their professionals. Although abandonment was most commonly reported in terms of a lack of follow-up appointments, one person with MND expressed a further sense of isolation in view of the lack of interest that was demonstrated by her general practitioner. Reportedly she had consulted the same physician for many years and had established a good rapport with him. Following the diagnosis of MND however, he no longer seemed concerned about her well-being. For example both participants from this Unit stated that the general practitioner was unwilling to make a house visit on one particular occasion when an emergency arose, and when the patient required a nebuliser urgently, he took longer than one month to provide a letter of motivation to the Medical Aid. As a result both the person with MND and her daughter felt that the abandonment by the general practitioner signified the loss of a support system in which they had trusted.

Finally with regard to truth-telling, all participants stated that because of the blatant manner in which information had been delivered, there was never a need to question the integrity of the content that HCPs had reported. Participants were therefore in no way concerned about lies or any distortions of the truth. Of equal importance however, while all individuals stated that they would rather be told the truth than be protected by the professional in terms of withholding information, they did suggest that HCPs need to soften the delivery of information and adopt a more compassionate and sympathetic approach when interacting with their patients.

The second component of information transmission regarding communicative content, looked at the information provided to participants about intervention and future expectations for living a life with MND. According to all participants no recommendations or referrals for rehabilitation were made by any professionals, with most of them stating that nothing could be done to help persons with MND. As a result many individuals with MND reported an initial sense of hopelessness and isolation. However following research on the Internet all participants became aware of the importance of rehabilitation. Most Units therefore made their own attempts to locate various rehabilitation therapists and approached local professionals near to their homes. For those participants who did attend rehabilitation, mixed responses were elicited in terms of their perceptions regarding the management that they had received. For example both participants from Unit 1 regretted having made the decision to consult local therapists because the person with MND perceived the experience to be more traumatic than beneficial. According to the daughter, the physiotherapist that was consulted treated the patient despite having stated that she knew very little about MND. After approximately three sessions a mutual decision was made between the daughter and her mother to refrain from receiving this intervention. Such a decision was based on the fact that the person with MND cried with pain during each session and therefore questioned the effectiveness of physiotherapy for MND. At the same time as this particular experience, the person with MND also attended a local speech-language pathologist. This professional too stated that she knew very little about MND as her major caseload was one of paediatrics, and informed the patient and her daughter consequently that nothing could be done from the perspective of speech-language pathology in order to provide intervention or support. It was thus suggested that it would be a waste of their time returning for future appointments, as speech-language pathology intervention would reportedly "*have no achievable objectives*". Further questioning on the part of the researcher revealed that there was no discussion from this speech-language pathologist around the possible use of alternate and augmentative communication in the future, or potential swallowing problems and how they might be managed. As a result of this encounter as well as that with the physiotherapist, both participants believed that nothing could be done for the plight of persons with MND and their families. Upon discussing this finding with the researcher, the daughter learnt that rehabilitation therapists often vary in their interests and the types of populations that

they treat. She therefore felt very strongly that healthcare consumers should be informed of these variations in practice, because as a member of the public she believed that any physiotherapist or speech-language pathologist would have been competent to treat patients with MND. Hence when the speech-language pathologist informed her that intervention would be of no value she did not question this recommendation. Moreover this individual also suggested that because a neurologist is usually the first professional to be consulted, it should be his/her responsibility to not only refer the patient for rehabilitation but also to the appropriate therapist that is knowledgeable in the field of MND. Finally for the daughter of this Unit, the question arose as to why the overall management of MND seems to be inferior relative to any of the other neurodegenerative diseases.

In relation to the negative experiences that Unit 1 reported regarding rehabilitation, the participants from Unit 3 stated that although their consulting professional had not made referrals for any type of therapeutic intervention, a representative from the MND Association of South Africa did suggest that a speech-language pathologist be consulted. However when investigating this recommendation the Association was unable to provide them with any contact details for a speech-language pathologist who could assist the person with MND, and participants from this Unit therefore failed to pursue this avenue any further. Of their own accord they did however consult a local physiotherapist. After attending physiotherapy for several sessions this person with MND also decided to discontinue treatment because she was reportedly dissatisfied with the services that were delivered, and failed to note any real improvements in her physical condition. The focus for this particular Unit then shifted from a medical perspective to more alternative or non-medical management, whereby the person with MND began consulting a Reiki healer and attending consultations for "drug therapy".

In the case of Unit 5, this individual who was newly diagnosed with MND at the time of the interview also received no recommendations or referrals from her HCP. Although this person with MND expressed her desire to attend rehabilitation because of the fine motor difficulties that she was experiencing, she indicated uncertainty in terms of locating the appropriate therapist. In addition she also acknowledged that although she was aware that her speech would eventually become impaired, she was

unsure whether she should consult a speech-language pathologist prior to the onset of speech deterioration or only once she began to experience difficulties in this regard. She thus questioned whether the diagnosing professional was himself aware of the recommendations that should be provided to individuals who are newly diagnosed with MND.

Positive experiences regarding rehabilitation were revealed in those Units (Units 4 & 6) where therapists who had prior experience with MND were consulted. For instance persons with MND from both of these Units consulted speech-language pathologists who had worked with similar patients previously. Not only did these speech-language pathologists reportedly alleviate some of the frustration that had arisen as a result of the impaired communication, but also both persons with MND commented on the fact that because their respective speech-language pathologist knew about the disease, they were more compassionate and understanding than any other professional that had been consulted. In addition the information and assistance that was provided by these speech-language pathologists was perceived as practical and entirely appropriate for the challenges faced by persons with MND. For example, the person with MND from Unit 4 commented on the way in which the speech-language pathologist modified communicative interactions by allowing him to converse with her using the office computer. Also participants from Unit 6 commented on the benefits of the speech-language pathologist's step-by-step explanation of the different stages of swallowing, as both individuals then understood the reasoning behind the various swallowing techniques that were introduced by the therapist. As a result of these positive experiences participants from both Units 4 and 6 reported that speech-language pathology intervention was one of the most beneficial of all the different rehabilitative therapies. Participants from Unit 4 and the daughter from Unit 6 also stated that the contributions made by their respective speech-language pathologist were the most valuable in terms of enhancing quality of life.

In addition to the tangible benefits provided by speech-language pathologists, the hope placed on speech-language pathology intervention was also apparent in Units 1, 2 and 3 despite these persons with MND having little or no previous contact with this form of rehabilitation. For example the person with MND from Unit 2 stated that the communication impairment had created significant tension between her and her

friend, thereby affecting both individuals' quality of life. She thus believed that had she consulted a speech-language pathologist, some of the pressures of the situation may have been alleviated by virtue of improved communication between herself and her friend. However despite this person's desire to attend speech-language pathology intervention and rehabilitation in general, no therapists were contacted due to financial reasons. Medical costs had become a concern for this particular Unit ever since the person with MND was forced to leave paid employment and the associated medical benefits. Furthermore not only was the actual consultation charge problematic for this individual, but also the transportation required to and from home. Given that this person was bed-ridden an ambulance service was required to transport her, however at a charge of approximately two thousand South African Rand per trip this idea was not feasible. The belief that speech-language pathology intervention had the capacity to alleviate tension between individuals was also echoed in Unit 3. The husband from this Unit stated that he would have liked his wife to consult a speech-language pathologist because the frustration resulting from the communication impairment was so intense that any possible offer of hope would be worthy of investigation. Furthermore he was even prepared for his wife to abandon the use of oral language and adopt a form of alternate and augmentative communication if this modality was going to enhance the quality of their communicative interactions. Similarly on the basis of information provided by the researcher, the person from Unit 1 stated that she too would have liked to pursue speech-language pathology further despite the recommendation of the speech-language pathologist that she had consulted initially. According to this individual she was prepared to try any form of intervention in order to reduce the isolation, frustration and resentment that had arisen as a result of the communication impairment. The burden of the impairment for this person was thus captured unequivocally in her statement, "*MND would be much easier to cope with if it existed like it does but with normal communication*".

Following on from questions pertaining to rehabilitation, the researcher asked participants whether any other forms of management had been discussed, and whether factors such as possible side-effects, effectiveness, and implications of treatment had been considered. Although the recurrent idea that "*nothing could be done*" meant that many of these questions did not apply, the person with MND from Unit 4 stated that the one professional whom he had consulted suggested a certain drug to try and

slow the progression of the disease. When prescribing this drug the HCP informed the patient that it was very costly, however on collecting the prescription the person with MND stated that it was so expensive that he realised financially he would be unable to sustain on-going treatment. In addition the medication also made him sick, as confirmed by the severe side-effects documented on the drug insert. Consequently the person with MND discontinued the use of this medication and felt strongly that the professional should not only have been more specific about the cost involved in taking the drug, but also the severe side-effects should have been explained in detail. He believed that had this information been provided he would have been able to make an informed decision about whether or not he wanted to take the drug, and whether or not he was prepared to spend so much money on the medication. The only other recommendation that was raised with regard to management occurred in Unit 6. The neurologist reportedly informed the person with MND and her daughter that although no forms of treatment are available for MND, towards the end stage of the disease when the pain becomes too unbearable morphine could be administered. Although it was acknowledged that the HCP was trying to reassure the person with MND, this recommendation was apparently very overwhelming for the individual and she subsequently began to fear the future in anticipation of the extreme pain that would be experienced.

Given that the MND Association of South Africa is one of the only support systems available for persons with MND and their families, participants were asked to comment on this organisation and support groups in general. According to all Units, no persons with MND were informed about the Association and instead either came to learn of it from family or friends, or from searching the Internet and making the relevant telephone calls. Reportedly when one diagnosing professional was asked whether an Association existed he was unable to provide an answer. Half of the Units thus stated that just as one would expect the diagnosing HCP to make referrals and to the appropriate professionals, so too should they inform patients about the Association. In addition to the MND Association of South Africa, several participants also raised the need for a support group where persons with MND and their families can meet other individuals in similar circumstances, and learn more about the disease and how to cope on a daily basis. One family member also suggested the need for a MND directory. According to this individual much time and money was wasted on



consulting different HCPs, especially rehabilitation therapists who informed her and her husband that either nothing could be done for them or that he/she knew very little about the disease. It was thus suggested that if a directory exists listing all HCPs who work in the field of MND, and it is distributed amongst professionals and the MND Association of South Africa, as well as patients diagnosed with the disease, then not only can referrals be made to the appropriate HCPs but also patients and their families can be offered the opportunity to make more informed decisions about who they wish to consult.

With regard to informed decision-making based on knowledge acquired from a variety of sources, participants fell into two broad categories. The first category included the majority of persons with MND and their family members who stated that they were confident to make decisions in view of the information that they had attained. Of these participants some felt that by virtue of their own research and sourcing of literature they were well informed about MND and therefore able to make their own decisions, while others felt that the quality and quantity of information provided to them was sufficient because few decisions about the future needed to be made in view that no assistance is available for persons with MND. The second minority category of individuals, or those who felt unprepared to engage in a decision-making process, expressed their dissatisfaction with the information that was provided. These participants reported that despite having sourced their own information, that which had been provided by HCPs was completely inadequate upon which to base decisions. As one participant stated, professionals overestimate the knowledge of members of the public and assume that patients are well-informed. Instead HCPs should work on the assumption that patients know very little at the outset of a disease and therefore need to be provided with even the most minor details that may be perceived by the professional as being insignificant.

Associated with informed decision-making, participants were also probed about the nature of the decision-making process. The main types of decisions that were raised included the possibility of moving into a home or institution, the correct timing in terms of contacting Hospice, and whether or not to engage in alternative medicine. However because persons with MND and many of their family members initiated most of these ideas and plans, HCPs played a limited role in the decision-making

process. Moreover the vast majority of persons with MND stated that they were excluded from decisions regarding their lives. Although the person with MND may have been present with a family member when decisions were made, they were not always involved actively in the process because their opinions and preferences were not considered. For these individuals this exclusion was perceived as a direct result of the communication impairment, and they therefore expressed emotions such as annoyance, anger and resentment in people making decisions about their lives for which they were not a part. In contrast however, when the family members were asked about collaborative decision-making many of them felt that decisions were made either together or by the person with MND alone. And thus variable perceptions between persons with MND and their family members were once again highlighted.

Finally although the literature documents the various decisions that need to be made by patients with MND (e.g. ventilation and percutaneous endoscopic gastrostomy), hardly any participants made reference to these options. Only Unit 6 discussed end-of-life decisions, specifically in terms of ventilation. The daughter from this Unit informed the researcher that ventilation was not an option because the diagnosing HCP had suggested that they avoid this process. According to this professional ventilation only prolongs a part of life that should not be prolonged. On this basis both the daughter and her mother were against the idea of ventilation to sustain the life of the person with MND. Moreover when asking participants about a living will, most persons with MND and their family members reported that they had either drafted the document or were aware that it should be done. Furthermore Hospice was apparently the driving force behind initiating this process. Only one Unit (Unit 1), despite being in contact with Hospice, was completely uninformed about a living will and did not know what it meant.

#### ➤ **Receiving Information**

*The communicative behaviours of the professional acknowledge the needs of the person with MND and/or the family member*

The next component of this section regarding communicative content investigated the competency of professionals in receiving and acting on communicative contributions made by participants. Although all participants were satisfied with the professionals'

abilities to listen attentively, more than half of these respondents stated that HCPs usually only listened to the family members and failed to focus on the person with MND. Many participants believed that this occurrence was a direct result of the communication impairment, with the daughter from Unit 1 stating that it was simply easier and more time effective for HCPs to communicate with a partner who is communicatively intact. While the person with MND from Unit 6 understood this rationale, she expressed frustration at being unable to convey her own thoughts or questions pertaining to information that had been provided to her. Likewise the person with MND from Unit 2 felt angry about the fact that she appeared to be treated as though she was stupid because she was unable to communicate. In addition the person with MND from Unit 1 believed that although communicative interactions with HCPs appeared to be effective because they occurred between the professional and a family member, they were in fact unsuccessful given that her personal needs and opinions were not acknowledged. In contrast however, participants from Units 3 and 4 reported that the alternative professionals and those in Germany not only listened attentively to the person with MND and his/her family member, but also offered sufficient time and patience for messages to be conveyed. As a result of this situation individuals from these two Units believed that professionals really did acknowledge the opinions of the person with MND and act on any decisions that he/she made. Moreover for the person from Unit 5, she also felt that the HCP had acknowledged her communicative contributions and opinions because appointments were attended alone and there were no other individuals with whom the professional could communicate.

Following the probes regarding the ability of HCPs to listen attentively and acknowledge persons with MND and their family members, all participants believed that minimal opportunities were provided for them to ask questions to the appropriate professionals. As a result most family members took it upon themselves to ask the HCP questions whenever they arose. For many persons with MND however, they reportedly refrained from asking questions because of the length of time taken to communicate and the perception that professionals appeared too busy. A minority of persons with MND also stated that they had no questions to ask HCPs because they had been informed that nothing could be done to help them, and they therefore saw little value engaging in an activity that would have made no difference to their

situation. Consistent with the findings from Units 3 and 4, all participants from these Units reported that the alternative professionals and those in Germany offered both the person with MND and the family member numerous opportunities to ask questions. In addition these HCPs were reportedly patient while the person with MND engaged in communication, and they took the time to reply to questions that had been posed. Furthermore while participants from Unit 4 were in Germany the wife made a list of their queries, concerns and uncertainties. Although feeling embarrassed to ask all of these questions in the fear of wasting the professional's time, both the person with MND and his wife were put at ease after being reassured by the HCP that he would answer their every question. The wife from this unit added that she was amazed by the professional's willingness to give of his time in order to answer their questions. She expressed her doubt as to whether HCPs in South Africa would respond in the same manner, stating that their 10 to 15 minute appointment is perceived as too important and they are therefore unlikely to accommodate lengthy question and answer sessions. As a result of this experience for Unit 4 and a similar experience for Unit 3, all participants from these Units felt that the alternative professionals and professionals abroad had provided them with a sense of comfort beyond the facts of MND. However for the remaining participants no sense of comfort was perceived, with one person with MND suggesting that HCPs do not know how to support individuals who are unable to respond to them verbally.

Finally in terms of confidentiality, all participants perceived this aspect of practice to be unproblematic. Both persons with MND and their family members felt that according to their knowledge, personal information that HCPs had acquired about them had not been disclosed inappropriately.

➤ **Integration of Subsection**

*Additional comments relating to communicative content*

On the basis of the investigation made with regard to communicative content, the general findings highlighted that individuals were dissatisfied with the quantity of information provided about the nature of MND. This perceived inadequacy of information therefore resulted in many participants being prevented from gaining a detailed understanding of the facts relating to MND, and thus experiencing a sense of harm. Moreover harm was also perceived by virtue of the cold, blatant and

unsympathetic manner in which HCPs imparted information. These overall negative findings were however in contrast to the responses provided by a small minority of participants who had consulted alternative professionals or professionals abroad. Individuals who had consulted such HCPs were satisfied with both the quality and quantity of information provided, and they failed to perceive the behaviours of these professionals to be harmful or damaging. In addition, unlike the harmful or damaging experiences that were reported throughout most of the Units, no participants raised concern of lies, dishonesty or hidden information on the part of HCPs.

In terms of information pertaining to management, findings revealed that no recommendations or referrals had been made for either rehabilitation or consultation with the MND Association of South Africa. Participants therefore searched for their own options in terms of management, and consequently contacted local rehabilitation therapists and the MND Association of South Africa of their own accord. For those individuals who consulted HCPs who were unfamiliar with, and inexperienced in the field of MND, negative experiences were reported in terms of rehabilitation. In such cases treatment ceased to continue because either the participant felt that the therapist was not competent in treating MND, or because the HCP stated that there were no benefits of rehabilitation for persons with MND. For those individuals who consulted therapists with previous exposure to MND however, rehabilitation was perceived in a more positive light and speech-language pathology intervention was reported to be the most beneficial of all the available therapies. On the basis of these positive reports, rehabilitation in general and more specifically speech-language pathology was perceived as a vital component of the management for MND, with some participants suggesting that it is the only form of intervention for this disease that can enhance quality of life and make the person with MND feel as comfortable as possible. Further to rehabilitation, participants raised the need for a support group where persons with MND and their families could meet other individuals in similar situations and learn more about the disease. Also the need for a directory of all professionals involved in the management of MND was highlighted. Finally the lack of information reported by most participants was perceived to have had a significant influence on the decisions that persons with MND are required to make. Although few participants had discussed any major life decisions, for those persons with MND who had engaged in the decision-making process they felt excluded from the

decisions that had been made surrounding their lives because they perceived their family members as taking control of the situation.

The ability of HCPs to receive and act on information transmitted by participants revealed that professionals seldom listened to and acknowledged the communicative attempts and opinions of persons with MND. Professionals appeared to prefer communicating with the communicatively intact family members, and frequently avoided interacting with persons with MND. In addition while HCPs were perceived as inept in providing participants with opportunities to ask questions, most family members were adamant to raise their queries and concerns even if such opportunities were not provided. For persons with MND however, many individuals refrained from asking questions because of the time taken to communicate their ideas. These findings were once again in contrast to those reported by the participants who consulted alternative professionals or professionals abroad. In such cases participants reported numerous opportunities to ask HCPs questions, and persons with MND were perceived to be treated as an equal during communicative interactions.

### ***Subsection c – Healthcare Consumer-Professional Relationship***

#### **➤ Person with MND**

*The communicative behaviours of the professional acknowledge the individual with MND as a person*

The first section pertaining to the healthcare consumer-professional relationship considered the individual with MND and whether he/she was perceived as being treated like a unique person. Although all individuals with MND believed that professionals had not treated them with warmth, friendliness, empathy and compassion, some of their family members did not perceive any problems in this regard. Several persons with MND felt that HCPs were uncompassionate because not only did they have limited time available for their patients, but they also demonstrated little concern for individuals with the disease knowing that they would be unable to save them by providing a cure. When questioning participants about the availability of HCPs, all individuals reported inadequacy in this area. The majority of participants commented on the fact that appointments were very rushed, which was especially problematic for persons with MND whose communication was slow and effortful. Furthermore many participants reported a sense of isolation and loneliness in not

being provided with follow-up appointments. The friend from Unit 2 for example suggested that because there were no follow-up appointments with HCPs, there had been no sense of continuity or the development of rapport with any one professional. Thus the person with MND and the friend were left feeling very unsupported throughout the entire disease process. Moreover the person with MND from this Unit suggested that when professionals establish that a patient has a terminal disease like MND, they believe there is no hope and give up on the patient with the result that no support or encouragement is provided for the individual. This perception was encapsulated in the following statement made by the person with MND from Unit 2, *“They can’t be bothered I take up too much of their time. I am a nuisance and a burden and an annoyance”*. The concern around availability of HCPs for Unit 5 related to the fact that the professional had said to the person with MND that she should phone him if any changes occurred in her condition. While this instruction was perceived initially in a positive light highlighting the willingness of the professional to support her, she was later concerned that any phone calls she made would be billed as a consultation, thereby leading to financial implications on her part. Finally although the person with MND from Unit 6 reported a sense of being unsupported by professionals, she expressed her content in the fact that her family supported her and therefore did not feel the need for any additional assistance from HCPs.

Given that the opinions, decisions and preferences of persons with MND were seldom acknowledged by professionals and occasionally even their family members, many persons with MND felt that they were not valued and respected as individuals. Professionals never asked for the thoughts of persons with MND, but simply addressed their family members directly. Moreover several persons with MND also stated that family members were in fact inadequate in assisting them to reveal their true opinions and preferences about the future. In the case of Unit 2 however where the person with MND did voice her own preferences, a clash in opinions occurred between her and her friend. Although both the friend and a representative of the MND Association of South Africa felt that a home was worthy of consideration because the caregiving role had become too burdensome for the friend, the person with MND expressed her wish to die at home. In view of this conflict the person with MND expressed her discontent at the fact that her opinions had been overlooked as

arrangements for a home had been made against her will. Consequently the individual with MND from this Unit believed that she had been excluded from all decisions regarding her own life. A further occurrence relating to perceived disrespect for decision-making occurred in Unit 4. According to participants from this Unit, when they informed the HCP that they would be travelling to Germany for stem cell therapy the professional reportedly stated that they should not waste their money searching the world for a cure. Following this comment both participants reported a sense of hopelessness and resentment at the fact that the HCP had failed to understand and respect that when persons are faced with a terminal illness they are willing to try any type of treatment that offers hope. Related to the idea of hope, all participants agreed that professionals should not give false hope but instead offer healthcare consumers some form of encouragement in order to try and enhance the self-esteem of persons with MND and their family members. A common response elicited from persons with MND when asked about hope and encouragement, was that professionals often fail to provide hope or optimism and give the impression that they believe that MND is a death sentence. This belief was encapsulated in a statement made by the person with MND from Unit 1 who stated, "*What is there to encourage, there is no hope*". For the person with MND from Unit 3, she believed that although she was taking a risk by engaging in a "drug therapy" for which very little is known, it was however worth the chance in that it provided her with hope and the possibility of a cure. Moreover the wife from Unit 4 stated that when such destruction strikes one's life and family, any steps will be taken in an attempt to improve the situation. As a result she and her husband went through a stage when they placed their hope on the use of illegal substances. According to an Internet site various substances although illegal, had been proposed as a cure for MND. Out of pure desperation participants from this Unit therefore accessed these substances in the hope that they would bring relief to their situation.

With regard to honesty and truth-telling, all participants highlighted the fact that HCPs were very honest about the disease and the final outcome. The only experience of dishonesty, or perhaps more a case of false hope occurred in Unit 2. During the period following the diagnosis of MND, a friend organised for a homeopath to assess the person with MND in her home. Following the assessment the homeopath stated that the person had been misdiagnosed and did not present with MND, and that



through his treatment he would be able to cure the disease. This re-diagnosis thus raised hope for both the person with MND and her friend, such that both participants experienced a sense of relief. However when investigating this treatment option further, the person with MND realised that financially it would be impossible for her to attend appointments with the homeopath. Despite the sense of relief that both participants reported following the homeopath's diagnosis, in retrospect the person with MND felt that this HCP had been dishonest and given her false hope about her life. Further probes about truth-telling revealed that participants were satisfied in that professionals did not lie. However although HCPs were perceived as honest in their provision of information and explanations, the manner in which such content was delivered was reportedly blunt, callous and nonchalant. The majority of participants therefore perceived information delivery as burdensome and damaging. In addition many participants made comments such as, "*They should soften the blow*", "*They need to couch (sic) you through the process*" and "*They shouldn't be so harsh*".

The results presented for the healthcare consumer-professional relationship thus far applied solely to medical and rehabilitative HCPs. However significant differences were noted in the relationships that were established between participants and alternative professionals or rehabilitative HCPs with experience in the field of MND. Reportedly all participants who consulted this group of professionals commented on the warmth, friendliness, empathy and compassion provided to both the person with MND and his/her family member. These professionals also offered encouragement and support, and were prepared to go out of their way to assist the person with MND in any way possible. In addition participants felt that this group of professionals were truly concerned about the health and well-being of the person with MND. Unlike the findings related to the medical and allied medical HCPs, the alternative professionals and rehabilitative HCPs with experience made a point of acknowledging the decisions, opinions and preferences of persons with MND as well as their family members. Information delivery was also perceived in a more positive light for persons who consulted these professionals. Not only was information imparted in a more caring and understanding manner, but it was also acknowledged that members of the public are not as knowledgeable as their professional counterparts. Finally participants were questioned about their views on the perceived value of the person with MND as a unique individual. Although persons who consulted medical HCPs

perceived themselves as inferior and of little value in the patient-professional relationship, individuals who consulted alternative professionals and experienced rehabilitative HCPs reported a sense of equality in the relationship and a feeling of being a valued member of the Unit.

➤ **Family Member**

*The communicative behaviours of the professional acknowledge the family member as a person*

With regard to the healthcare consumer-professional relationship in terms of family-members, significant differences were established regarding how persons with MND were perceived to be treated by professionals, versus how family members were perceived to be treated. The majority of participants stated that family members were treated with greater warmth, friendliness, compassion and support. Also the opinions, preferences and decisions of family members were acknowledged and respected to a greater extent. According to several persons with MND, these marked differences in the way in which participants believed they had been treated during consultations were a result of the communication impairment. The perception that persons with MND were unequal or inferior communicative partners was highlighted in Unit 1 by virtue of a comment made by the daughter. Reportedly the person with MND was treated by professionals like a sick baby or young child who was unable to speak for herself, whereas the daughter was treated like a competent adult capable of self-determination and communicating her own thoughts and ideas. However these perceived differences regarding the behaviour of HCPs were not always consistent between the person with MND and his/her family member. For example in the case of Unit 2 the person with MND perceived the representative from the MND Association of South Africa to have treated her with less warmth and compassion than the way in which her friend had been treated. Conversely the friend reported that there were no differences between the interactions with herself and the representative, and those between the person with MND and the representative. As a result for this person with MND, she was therefore resentful of her situation because she perceived both her friend and the representative to be in opposition to her. Consequently this individual believed that whilst her friend had been viewed as the “*poor victim*”

having to cope with such a terrible situation, she had been labelled as a nuisance and of little value in the Unit.

Contrary to the general finding that persons with MND were treated with less warmth, compassion and support than their family members, the participants from Unit 4 reported a different experience. According to the person with MND, his wife had not been cared for or supported by professionals during the disease process as most of the attention had been focused on him. Furthermore this attention was not seen in a positive manner because he too perceived the HCPs to be uncompassionate and cold towards him and his wife. This lack of support was reinforced by comments made by the wife, who stated that professionals had treated both her and her husband in a disregarding and disrespectful manner. However she indicated that because she was not the patient she did not think that she had the right to expect HCPs to support her and be concerned about her, after all she added, *“Its not about me, there should be a support group where I can be consoled”*. In contrast, with regard to the stem cell therapy experience the wife from this Unit reported that the professionals in Germany were instead very kind, caring and compassionate to her. While this behaviour on the part of the professionals was appreciated, the wife stated that she felt uncomfortable when HCPs focused on her because she was concerned that they were wasting their time. She believed that the time HCPs spent with her could have been dedicated to her husband. Subsequent to this experience, both the person with MND and his wife felt that South African HCPs have much to learn about quality healthcare consumer-professional relationships. Likewise similar findings were echoed in Unit 3 when medical and rehabilitative professionals were compared with alternative professionals. Both participants from this Unit stated that at the outset of their MND journey there was a definite distinction between the way in which the person with MND was treated by HCPs, and the way in which her husband was treated. However once this Unit rejected traditional or conventional medicine and began consulting alternative professionals they were both treated equally and acknowledged that in their own contexts they were faced by different yet significant challenges each deserving of support, respect and compassion.

Probes relating to truth-telling, honesty and lies revealed the same findings as those yielded for the healthcare consumer-professional relationship in terms of the person

with MND. All participants reported that HCPs were honest and did not withhold information or distort the truth. The manner of information delivery was also perceived as blunt, untactful and a burden for many family members. Finally no concerns were raised with regard to confidentiality.

➤ **Integration of Subsection**

*Additional comments relating to the healthcare consumer-professional relationship*

The investigation of the healthcare consumer-professional relationship revealed that while persons with MND were perceived as being devalued and disrespected by HCPs, the quality of the relationship between family members and professionals was viewed as having greater equality. Thus although all persons with MND were dissatisfied at the inability of HCPs to demonstrate warmth, compassion, friendliness, support and availability towards them, they believed that these constructs were in-situ in the relationships between their family members and professionals. Both persons with MND and their family members posited that professionals had failed to acknowledge and respect the decisions and opinions of persons with the disease. Such disrespect on the part of HCPs was perceived to be a direct result of the communication impairment and length of time taken by persons with MND to convey their messages. Furthermore, participants felt that a possible fear on the part of HCPs to engage in communicative interactions with individuals who were unable to reply or respond to them may have further contributed to this disrespect. In some Units persons with MND also perceived family members as failing to respect their decisions, thus creating tension and frustration within the family unit. In terms of honesty, truth-telling, and the withholding of information, all participants were satisfied with this aspect of the healthcare consumer-professional relationship, although the manner of information delivery was perceived to be damaging. In contrast to the general findings established in this section, the common belief regarding alternative professionals and the HCPs in Germany was that regardless of who they interacted with, albeit persons with MND or their family members, warmth, compassion, support, respect and honesty prevailed. Those individuals who consulted such HCPs therefore perceived themselves as equals and the healthcare consumer-professional relationship to be of a high standard. Similar findings were also noted

for those HCPs who were practising in South Africa and had already acquired knowledge and experience in the field of MND.

***Subsection d - The Person with MND as a Communicator***

➤ **Transmitting Information**

*The person with MND is able to transmit messages effectively*

The success of the person with MND as a communicator was first investigated in terms of eliciting perceptions regarding his/her effectiveness to convey messages. Despite the presence of impaired speech and/or paralinguistic features, all participants reported that the person with MND did his/her best to communicate irrespective of the modality utilised. For those individuals with a degree of movement of the hands, participants stated that the person with MND also relied on the use of non-verbal language to facilitate communication. In terms of topic initiation, apart from Unit 5 where the person with MND presented with relatively intelligible speech, all other persons reportedly demonstrated a severely reduced ability to initiate conversation. Most persons with MND stated that within the healthcare encounter and communicative situations in general, they will only engage in conversation when an individual speaks to them. Furthermore the daughter from Unit 1 added that her mother was not empowered to initiate conversation with HCPs, because her communicative attempts were very time consuming and she did not want to waste the professional's time. Hence in general the process of turn-taking and the natural flow of conversation was restricted by virtue of the limited output offered by persons with MND.

When probing about topic adherence, persons with MND and their family members indicated that the question-answer nature of communication between the person with MND and the HCP meant that it was relatively easy to adhere to the topic of discussion. Many family members perceived communication with the person with MND to be very one-sided. The daughter from Unit 1 highlighted this perception when she stated that her mother was trapped in a body which would not allow her to do or say anything, although her mind was still so active. The handicap surrounding the communication impairment was further reinforced when the friend from Unit 2 made the following comment, "*The lack of speech paralyses you*". As a result of this communication paralysis, the daughter from Unit 1 reiterated the fact that breakdowns

in communication that occur between persons with MND and their HCPs are inevitable, and that individuals should therefore accept that miscommunications will occur during consultations.

With regard to communication breakdowns all persons with MND reported that although they were aware of occasions when HCPs had misunderstood them, they seldom attempted to repair these breakdowns because they took too long to rectify, were too effortful to rectify, and listeners (i.e. HCPs) often demonstrated a sense of impatience. Many persons with MND were therefore disillusioned to engage in conversational repair because it resulted in more frustration than satisfaction, and interactions often ended in the words "*just forget it*". Only one person with MND from Unit 4 stated that he is persistent in ensuring that his messages are received and understood, because he feels that he has every right to convey that which is on his mind. Moreover this individual informed the researcher that he occasionally requests permission to e-mail a HCP with his thoughts, concerns or questions, and that such professionals are reportedly very receptive to this idea of communication. In the case of Unit 3, the person with MND stated that although she would like to ensure that communicative partners understand her communicative contributions, she is uncertain how to engage in conversational repair because regardless of what she says or does, her speech will always remain unintelligible and difficult for listeners to follow. On this basis she therefore stated that she avoids communicative interactions and thus the associated need for conversational repair.

In the case of encounters with HCPs, almost all persons with MND stated that they no longer ask the professional questions about the disease or their future because most communicative attempts result in frustration and stress for all members of the Unit, including the HCP. For example in Unit 1 the person with MND stated that she does not ask professionals or her daughter any questions because of the annoyance and sense of failure that it creates. As a result of this decision she has not inquired about the difficulties experienced with her swallowing. In the case of Unit 3 the person with MND stated that just because she chooses to avoid communication, it does not imply that she has no opinion of her own. Before any consultation with a HCP she prefers to spend time with her husband conveying her concerns or questions so that he can ask the professional on her behalf. In the case of the Units with more effective

methods of communication, such as e-mailing in Unit 4 and intelligible speech in Unit 5, apprehension around asking professionals questions was not too great a concern. Both of these individuals indicated that they would not hesitate to ask a HCP any questions that might arise, although in Unit 5 the person did feel that questions were insignificant because the answers would not change the finality of her situation. Furthermore in view of the frustration, annoyance and fear of failure when asking HCPs questions, most persons with MND also stated that they no longer speak their mind or convey their opinions regarding their health and well-being because they are certain of the negative repercussions that are likely to arise in terms of the communicative interaction. Consequently some individuals with MND even reported being untruthful about their health, and stated that it is simply easier to nod one's head to indicate that one is feeling fine than it is to suggest that there is a problem and have to provide an accompanying explanation.

Finally although more than half of the participants indicated that persons with MND were effective communicators despite their limitations, most communicative partners (particularly HCPs and family members) were perceived as ineffective and unsuccessful in terms of interacting in the presence of a communication impairment. Many participants reported that individuals including HCPs are too scared to communicate with a person whom they know will not be able to reply in the conventional manner. Also the fear of having to communicate using an alternate modality such as an alphabet board was perceived as so intense that it is simply much easier for the communicative partner to engage in avoidance. In the case of Unit 2 however, positive experiences were reported when the person with MND communicated with the priest and friends from her church. Such individuals were not only patient while the person with MND conveyed her messages, but they also created an atmosphere of ease where she felt comfortable to request clarification or ask a question even if the topic of conversation had already shifted. It was thus suggested that if communicative partners (i.e. HCPs) could demonstrate just a small amount of patience and interest in persons with MND, then these individuals (i.e. persons with MND) might feel more comfortable in sharing their personal thoughts, opinions and questions.

➤ **Receiving Information**

*The person with MND is able to receive messages and act on them*

When discussing the ability of the individual to receive information and act upon it, all participants stated that the person with MND was apt in listening to a communicative partner, thinking about and processing the input provided, and formulating his/her own opinions. Likewise persons with MND were perceived as receptive to any contributions made by HCPs in terms of the disease. However beyond this cognitive process, most persons with MND reportedly refrained from voicing their own opinions formulated in response to information that they had received. Furthermore the majority of participants stated that although there had been occasions during conversations when breakdown had occurred and the person with MND was required to seek clarification, he/she seldom engaged in a process of repair or asked questions about information that was difficult to understand. This reluctance was reportedly due to the fact that owing to the speed of communication, many persons with MND felt they were no longer able to keep up with the pace of conversation, and thus by the time they had tried to initiate repair the moment had already past. In addition because few communicative partners demonstrated a sense of awareness regarding the communicative interactions that transpired, they were unable to recognise the need for repair or the need to facilitate the person with MND who attempted conversational repair. Consequently many persons with MND reported feelings of doubt about their effectiveness as a valued communicative partner.

➤ **Integration of Subsection**

*Additional comments relating to the communication of persons with MND*

On the basis of the findings for this section of the interview schedule, it was revealed that the majority of persons with MND were reluctant to transmit information and therefore seldom initiated communication and avoided engaging in turn-taking or conversational repair. Despite all persons with MND being receptive to the input of others and formulating their own opinions, ideas, and/or questions about the disease, in the presence of poor communication few individuals with MND were empowered to voice or communicate their thoughts. In addition most communicative partners were viewed as unsuccessful communicators, and perceived as impatient and fearful



of interacting with communicatively impaired individuals. On this basis it therefore seemed that communicative transactions with persons with MND occurred in a vicious circle, whereby the individual would struggle or avoid initiating conversation, yet in instances where communication was initiated the communicative partners often failed to reciprocate effectively because of the possible fear or lack of skill associated with communicating with a communicatively impaired person. Moreover if the communicative partner did initiate conversation, breakdowns often occurred that were not repaired. Such breakdowns were seldom rectified because the time taken for the person with MND to attempt repair was not compatible with the speed at which communication occurs. Moreover the reported reluctance of the conversational partner to facilitate repair, or his/her lack of awareness regarding the need for repair also affected communicative exchanges. Hence the quality of interactions that occurred between the person with MND and his/her HCPs was compromised in part due to this individual's inability to transmit and receive information in the conventional manner.

### **Section C: Concluding Comments**

In response to the five specific questions that were asked to participants, a number of diverse responses were elicited.

The first question focused on whether or not participants perceived the communication impairment as having an impact on the overall management of MND. For Unit 5 the person with MND remained impartial because she felt that her communication abilities were still adequate and therefore had no bearing on the management that she had received thus far. In the case of Units 1 and 2 both persons with MND felt that had communication between themselves and their HCPs been more effective, then the entire management process and the promotion of their well-being may have also been improved. For example the individual with MND from Unit 1 suggested that she would have expressed her concerns regarding her swallowing difficulties had she had an effective communication modality in-situ. However effective in this case implied not only the person with MND being able to use the communication modality with competence, but also appropriate attempts made on behalf of the various communicative partners (e.g. HCPs and family members) to interact with this individual effectively. In addition the daughter from

this Unit also suggested that while the communication impairment had impacted on the management of her mother's disease, it may not have been her mother's poor communication per sé that had compromised the quality of the situation, but rather the fact that HCPs do not have the time to listen to impaired communicative attempts and do not know how to respond under such circumstances.

In terms of those participants who felt that the communication impairment had no effect on the management process, both respondents from Unit 3 were of this opinion. In this Unit participants believed that by virtue of the alternative professionals' supportive attitude, the person with MND was empowered to communicate her opinions thereby alleviating potential dissatisfaction and frustration that could have arisen during such interactions. Similarly the management of the person with MND from Unit 6 was also believed to be unaffected by the communication impairment. Since the daughter from this Unit engaged in all communicative interactions for her mother, the person with MND expressed satisfaction by virtue of the fact that she did not need to feel anxious about having to communicate herself. Although there was some reported frustration on the part of this person in that she was unable to express her own opinions, she felt relieved knowing that her daughter would take control of the situation. In addition, the daughter believed that the assistance she provided her mother enhanced the management that was received because she was available to speak to the HCPs on behalf of her mother and thus ensure more comprehensive care.

Finally both participants from Unit 4 and the friend from Unit 2 stated that the overall management of MND in South Africa is inadequate and feeble regardless of the communication impairment. The fact that communication difficulties impair interactions with HCPs was reported to be just another factor which compromises the quality and effectiveness of the management for MND healthcare consumers. Moreover because the professionals from Germany were so willing to engage in communication with the person with MND, participants from Unit 4 perceived the country to be well equipped and knowledgeable for managing MND in a competent and satisfactory manner. However South Africa was perceived as being far from the ideal in terms of its management for MND, particularly in view of the fact that HCPs were perceived to be ill prepared to communicate with communicatively impaired individuals.

The second question put forward to participants aimed to establish whether the communication skills of professionals were representative of their interactions with all patients regardless of the presenting illness, or whether the communication impairment was perceived to result in altered communicative interactions by HCPs. Although participants from the first two Units believed that the communication impairment had caused HCPs to treat persons with MND differently from other patients, the remaining participants did not share this view. Both persons with MND from Units 1 and 2 believed that HCPs had treated them with less respect and compassion than communicatively intact patients would have been treated. The daughter from Unit 1 confirmed this belief when she informed the researcher that during one particular consultation she was able to hear the HCP communicating with another patient. The professional's style of communication with this particular patient was in no way similar to that used with her mother. Reportedly the professional spoke to the person with MND as though she were a deaf child, whereas the other patient was addressed in an adult-like manner. In addition the daughter suggested that because the word "disease" has such negative connotations associated with it, it should be removed from the diagnostic label "motor neuron disease". Immediately people hear the word "disease" they think there is no hope for affected individuals and they therefore fail to acknowledge these persons as respected members of society. Furthermore for professionals who know little about MND they too may adopt this attitude and believe that because the condition is progressive and patients inevitably become dependent upon other people, they will eventually enter into a stage similar to that of the dependency in childhood, and thus be deserving of treatment and communicative styles that are associated with children.

Of the majority of participants who suggested that professionals are likely to treat their patients the same regardless of the disability or impairment that confronts them, many expressed that HCPs are poor communicators in general and demonstrate little warmth and understanding towards all of their patients. Thus regardless of the presenting health condition most patient-professional relationships are reportedly characterised by inequality and disrespect. In the case of Unit 6, the daughter stated that on one occasion her mother attended an appointment with a rehabilitative therapist where all patients were treated simultaneously in the same room. The therapist was reportedly rude and unprofessional, and spoke to all the patients with

little respect. She also interrupted patients' communicative attempts and failed to read or chose to ignore comments and facial expressions that indicated an individual's confusion or misunderstanding. As a result of such unacceptable behaviour, the person with MND and her daughter from Unit 6 thus decided to discontinue rehabilitation with this particular therapist and consequently sought intervention elsewhere.

For the third question, two broad categories arose in terms of members of the Unit perceived as being most effective in terms of communicating with persons with MND. The first category comprised family members who were close to the person with MND. All participants who fell within this response category stated that because family members spend so much time with the person with MND they are most familiar with his/her communicative style and communicative needs, and thus best understand the person's communicative contributions. The second response category included various other members of the Unit who interact with the person with MND less frequently. For example both participants from Unit 2 reported that the priest was the most effective communicator. Despite having no training to communicate with a communicatively impaired individual, he reportedly gave the person with MND sufficient time to convey her messages and he treated her like any other adult communicative partner. The desire to be treated in this manner was depicted in the following comment made by the person with MND, "*...because he pulls up a chair, sits and listens, and interacts. He is patient and treats me no differently*". In terms of Unit 4 both participants perceived HCPs from Germany and the alternative professionals that were consulted in South Africa as being most successful in terms of communicating with the person with MND. Reportedly these HCPs were caring and went out of their way to ensure that they understood the person with MND, regardless of the time it took to elicit and understand any communicative attempts. Finally a representative of Hospice associated with Unit 1 was also perceived as an effective communicator. According to the daughter this professional spoke to her mother in an acceptable manner and took the time to engage in adult-like conversations. In addition the person with MND from this Unit was in no way rushed to convey her communicative contributions, and nor was she interrupted during communicative attempts. Furthermore the person with MND stated that she was placed at ease when it became clear to her that the representative from Hospice was well-informed about

MND. She thus felt that every aspect of her impairment was well understood and accepted, and that her physical and emotional needs were also respected.

When questioning participants about the changes that they felt persons with MND should make to improve their communicative interactions with HCPs, a variety of comments were offered. Most commonly persons with MND reported that they do already try to communicate to the best of their ability, and thus no changes on their part were deemed necessary. Several family members reiterated this perception, suggesting that it is not the person with MND that needs to change but rather communicative partners (i.e. HCPs) must learn how to communicate with communicatively impaired individuals. According to one family member, communicative partners need to understand the frustration and anxiety that is experienced from the perspective of the person with MND, so that they can realise the invaluable role that they could play in facilitating communication with such individuals. Many family members also stated that although the person with MND may be doing his/her best to communicate, there are various personality traits that need to be emphasised. For example the daughter from Unit 1 felt that her mother needed to be more assertive in an attempt to convey her messages, while the daughter from Unit 6 suggested that her mother should be less ashamed of the communication impairment and more forthright in her communicative attempts. A further suggestion that was raised by the person with MND from Unit 4 and the husband from Unit 3, was the need for greater use of alternate communication modalities. Although the individuals with MND from both Units 3 and 4 were perceived to be communicating as best as possible using their available communicative skills, the need for a permanent alternate modality to augment communication was indicated. The final change that was suggested was put forward by both the person with MND from Unit 3 and the friend from Unit 2. These individuals reported the need to modify their communicative style, but were uncertain of the appropriate changes to implement. For example in the case of Unit 3 the person with MND stated that although she felt that she was ineffective in her communicative attempts, she did not know what changes she needed to make and how these changes should be implemented. As long as these uncertainties remained she stated that she would continue with her current method of communication, only hoping that she may get stronger and improve as a result of the “drug therapy”. In the case of Unit 2 the friend stated that although the

person with MND was doing her best to communicate, frustration regarding communication was rife. As a result of this frustration the friend explained that she became very angry and would scream at the person with MND. She even stated on several occasions that the frustration she experienced sometimes lead her to wish that she could kill the person with MND. Knowing that this behaviour was inappropriate the friend therefore expressed the need to find a more conducive manner of communicating with the person with MND. However she too was uncertain of the most effective changes that would be appropriate for addressing her situation.

For the final question, numerous contributions were offered by participants with regard to the changes that they perceived should be made by HCPs in order to improve communicative interactions with patients as well as the overall management of MND. The suggestions that follow have been reported Unit by Unit because despite the overlap that exists between various ideas, each contribution is reflective of each Unit's unique context and therefore warrants individual comment.

**Unit 1:** The person with MND from this Unit stressed on several occasions that HCPs need to learn how to communicate with communicatively impaired individuals. She believed that as a result of a substandard patient-professional relationship, the management that she had received had been inferior and unsatisfactory. Ironically however despite the many inadequacies reported by this person throughout the interview, she also added that because HCPs are so busy it is understandable if they fail to improve on their communication skills and their ability to establish quality patient-professional relationships. Contrary to this seemingly passive suggestion, the daughter felt very strongly about the recommendations that she discussed with the researcher in this regard. Firstly she expressed the need for all persons with a terminal illness and/or a communication impairment to be treated like adults. She was adamant that her mother who was probably older than any of the HCPs she had consulted, did not deserve to be treated like an incompetent child or deaf individual. Irrespective of the severity of the disease, the daughter believed that her mother was worthy of respect and compassion. Moreover the daughter also suggested that professionals who work in the field of MND need to shift their focus from death to life. While death may be an inevitable consequence of MND, professionals need to remember that so long as they are treating a person with this disease he/she is still

alive. Reportedly the attitude of HCPs should thus change and they should aim to bring hope and encouragement to persons with MND and their families.

The final comment made by the daughter was a suggestion to achieve more effective communicative interactions between persons with MND and HCPs. Given the reality of current day practice and the fact that professionals do not have the time to engage in lengthy interactions with communicatively impaired patients, alternate arrangements need to be made to ensure that HCPs nonetheless understand their patients, and are thus able to prescribe management appropriately. As a result of this need the daughter suggested that HCPs hire a nurse or assistant who has previous training or exposure to interacting with communicatively impaired individuals. Prior to the consultation with the professional this individual could take a case history or elicit follow-up information from the patient, which could then be handed over to the HCP at the time of the patient's appointment. By placing the communicatively impaired individual in a less pressurised situation with a person whose job it is to facilitate communication, the person with MND may feel more at ease to convey his/her thoughts, queries, questions and ideas, and thus feel more involved in promoting his/her own health and well-being. In addition the nurse or assistant could facilitate interactions between the HCP and the patient at the time of the consultation. More successful interactions between the patient and the professional may lead to greater healthcare consumer satisfaction, as well as more appropriate management on the part of the HCP because of him/her having a more accurate understanding of the person with MND.

**Unit 2:** For the person with MND from this Unit, her primary concern was that professionals need to learn how to listen to patients. She felt that if HCPs choose to immerse themselves in a career that entails interactions with communicatively impaired individuals, then they need to be tolerant and patient of such persons. Thus the person with MND stated that HCPs cannot expect to achieve healthcare consumer satisfaction if they are not prepared to spend the time required to learn about and understand their patients. The need to spend time with patients was further reiterated by the friend from this Unit. As this individual reported, professionals in general are too rushed and do not offer healthcare consumers sufficient time to express their concerns, especially when patients are communicatively impaired and require

additional time to communicate. In addition due to a lack of training in communication, HCPs do not know how to communicate with communicatively impaired persons. In order to avoid the fear that professionals possibly experience knowing that the patient cannot communicate in the conventional manner, they either resort to a cold one-sided communication style or simply ignore the person with MND as far as possible. Consequently the friend suggested that this behaviour creates an impression that the person with MND is perceived by the HCP as an “*imbecile*”. The final suggestion raised by the friend in terms of the overall management of MND was that the disease needs to be broadcast and made known to all members of society. This individual felt that if MND is better understood by professionals and the community by and large, then perhaps persons affected by the disease would be less neglected. Moreover the friend added that the impression that MND implies a sense of hopelessness and a period of time that simply needs to be lived-out until death, must be banished and replaced with one of hope and the possibility of giving persons with MND the best chance of maximising their quality of life.

**Unit 3:** According to the person with MND from this Unit, minimal changes by HCPs were necessary because she was satisfied with the management that had been received from alternative professionals. In terms of medical and rehabilitative HCPs however, the person with MND suggested that these professionals need to learn how to deliver information in a more tactful, supportive and compassionate manner, while still being honest and avoiding false hope. HCPs also need to realise that traumatic information which is imparted with no empathy and care can be burdensome and damaging for recipients. Likewise the husband from this Unit felt that because HCPs know that MND is terminal, instead of shunning the affected person and family they should rather give support and encouragement. Even if the professional does not give follow-up appointments due to the idea that nothing can be done to help the person with MND, a phone call to see how the family system is coping would be appreciated. As the husband suggested, knowing that HCPs care over and above the care offered by family members, strengthens the support system and facilitates the process of coping. After all he added, “*Its not only about paying for the doctor’s advice, he must care too*”.



**Unit 4:** The first change suggested by the person with MND from this Unit was the need for compassion. According to this individual on the day the diagnosis was delivered, he perceived the HCP as indifferent to the bad news that had just been imparted. The professional reportedly revealed no sense of compassion, understanding or care, and one might have thought that a diagnosis of a sore throat or influenza had just been made. It was also suggested by the individual from this Unit that professionals need to provide more information about the disease and inform healthcare consumers of all possible management options. As the person with MND suggested, had he have known more about MND at the outset of the journey, he would have been better able to plan his future and live his life to the fullest. Moreover he believed that the ability to make such preparations regarding one's life is a deserving right for all patients. Also in comparison to the experience in Germany, the person with MND felt that professionals in South Africa give up too easily. It was therefore suggested that HCPs need to learn from their German counterparts and acquire a spirit of motivation, determination, empathy and persistence in order to help patients in any way possible. If HCPs understood the destruction that MND forces upon a family system, then they may be more determined to assist their patients through the challenges that must be overcome.

In a similar fashion to her husband, the wife from this Unit suggested that HCPs in South Africa need to become more professional. Reportedly the HCPs abroad not only treated patients with greater respect, but their whole attitude regarding their work was one of devotion and commitment. In addition the wife confirmed her husband's statement that professionals give up too easily, and suggested that HCPs need to adopt a fighting spirit in order to enrich the life of the person with MND in any way possible. The need for guidance by professionals was also raised, and the fact that once such overwhelming information has been delivered, individuals and families are often immobilised and need to be guided in the correct direction. Patients should therefore not be left to seek intervention of their own accord otherwise they consult inappropriate or inexperienced professionals, which in turn leads to negative or unpleasant experiences for members of the Unit. In addition such unguided attempts to locate appropriate intervention can also waste a considerable amount of time and money on the part of the person with MND, which cannot be afforded given the financial concerns that a terminal illness poses for most individuals.

**Unit 5:** For the individual from this Unit, the need for greater information was of prime importance. More than just information about the disease, the person with MND felt that HCPs also need to keep patients informed throughout the work-up to the diagnosis. Although this individual acknowledged that other conditions need to be excluded before the final diagnosis can be made, and hence the professional may want to reserve his/her initial opinions, she felt that patients need to be informed of what tests are being performed and the rationale behind these tests. This particular individual went so far as to say that HCPs should inform patients of their suspicions right from the beginning, because she believed that after living months with the subtle yet progressive changes in terms of one's functional abilities, by the time a specialist is consulted "...you just know something is wrong". Although adding that this protocol may be viewed by some as inappropriate and potentially dangerous because it can cause unnecessary trauma in the event of an incorrect suspicion, this individual did however feel that she had experienced a great deal of anxiety and fear having to wait for test results. She would have therefore preferred to have been informed of all the possibilities at the outset of the consultation with the professional. In addition this individual also suggested that although HCPs should never withhold information from patients despite the potentially burdensome nature of the facts, they should however learn how to "*couch*" (sic) patients, and guide and support them throughout the entire disease process. Support for this person was perceived as important because she had only recently been diagnosed with MND and both her husband and her son had reportedly not yet accepted the diagnosis. Because she had not been informed of any available interventions or support systems, she expressed extreme isolation and the need for some type of guidance that would help her cope in such an overwhelming situation.

**Unit 6:** Initially the person with MND from this Unit indicated that no changes needed to be made to the management practice of MND, and nor did HCPs involved need to change. When questioning this individual further about this statement, she stated that in all likelihood professionals would not change their communication style and healthcare consumers should therefore accept current practice trends. Following further discussion however, the person with MND suggested that HCPs could improve their knowledge of the disease and focus more rigorously on establishing a cure. Ironically following this statement she also indicated that one should not blame

professionals for their ignorance about MND, because they cannot focus all their attention on this disease given the numerous other more common conditions that need to be treated. For this individual, she therefore believed that it would simply be easier if patients rather learn how to deal with the disease themselves and refrain from relying on HCPs, particularly with regard to a cure.

As in the case of the other Units, the daughter from this Unit also suggested that HCPs need to demonstrate greater compassion and care when interacting with their patients. In addition professionals need to engage in teamwork and learn how to communicate with each other. According to the daughter HCPs often present with different opinions placing the patient in a difficult situation, where the doctor for example may make one recommendation and the physiotherapist may make an alternate suggestion. Thus if better communication existed between HCPs then optimal management could be discussed, and patients would not need to burden themselves in trying to determine the most appropriate advice that should be followed. Furthermore improved networking between HCPs may also help to make information more accessible to patients. For example if HCPs in conjunction with the MND Association of South Africa were more proactive, an intervention directory and protocol for acceptable management could be created to benefit all members of the Unit. A final suggestion raised by the daughter from this Unit was the need for more research relating to MND. Such research should not only focus on finding a cure but also on improving health, well-being and quality of life for all Unit members. This suggestion was based on the fact that the daughter perceived MND to be taking a back seat in research in comparison to other conditions, and felt that it should no longer be considered as "*the orphan of all diseases*". As a result of the disease's current status, the daughter therefore suggested that people who have been involved with MND in any way need to find a forerunner or public figure that can be used as a platform for others to learn about the condition and its challenges.

### **3.2 FAITHFULNESS TO THE ORIGINAL DATA SET**

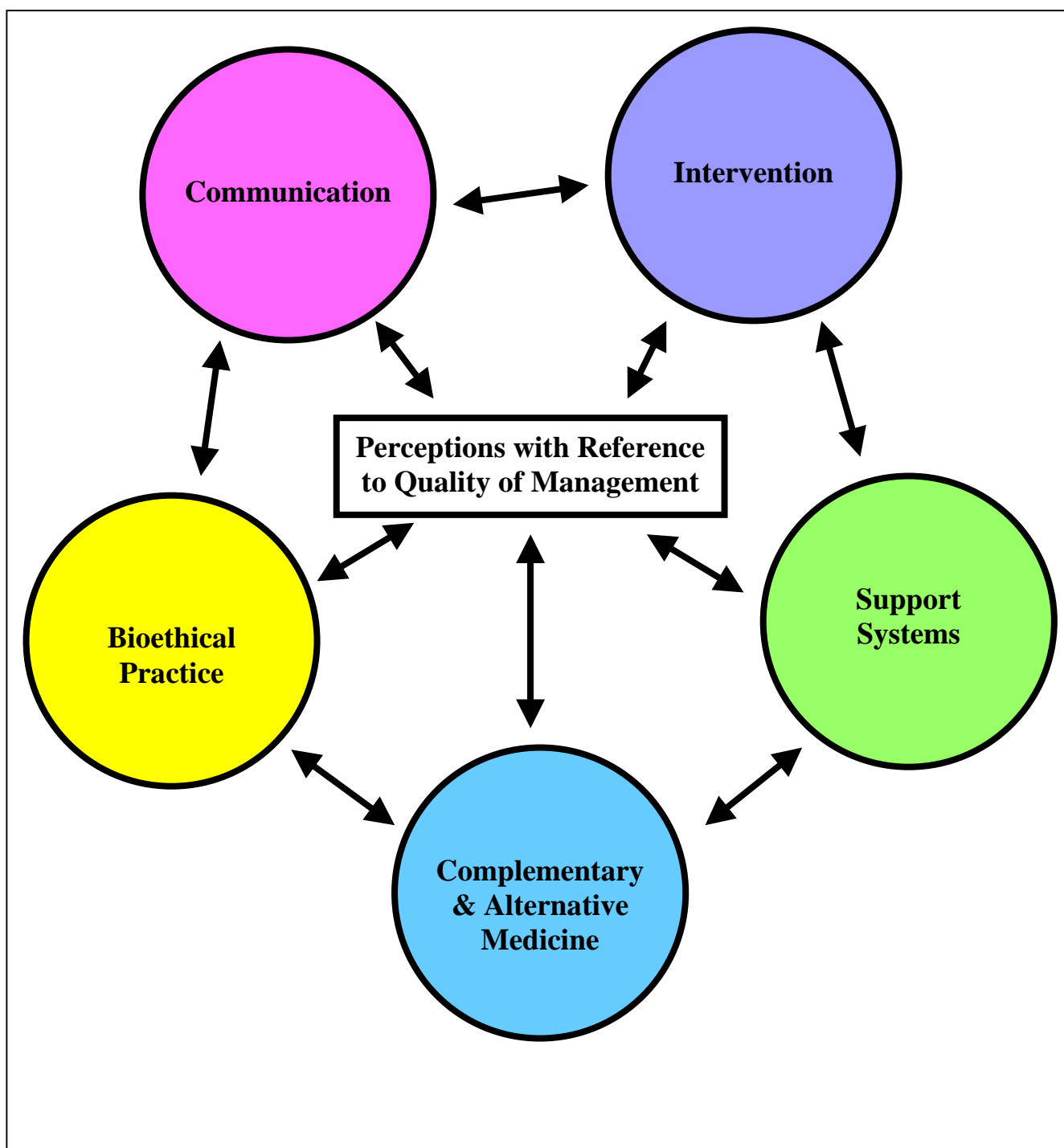
On the basis of the preceding section that presents the participants' perceptions of the medical and rehabilitative management of MND, it is thus apparent that solid evidence has been provided upon which to extrapolate the themes and discussion that are to follow. In accordance with the data management phase of analysis, a new data

set was created in order to organise the material into themes and sub-ideas (Ritchie et al., 2003b). Since this process was in fact performed as part of the researcher's data analysis phase, it has been omitted from the write-up of this study. However Appendix N contains the initial themes that were identified and common to all persons with MND and their family members. The rationale behind including this Appendix was to demonstrate to the reader not only how the data was managed, but also the process that was undertaken to reach the new data set in a manner that remained faithful to the original material. In addition Appendix N also depicts the frequency of occurrence of each initial theme as an additional means for protecting the integrity of the data. Although the literature states that numerical counts of recurrence are not the primary goal in qualitative research because they hold no statistical value, their relevance lies in conveying the collective content of the data (Ritchie et al., 2003b).

### **3.3 MAJOR THEMES**

Following on from the initial themes presented in Appendix N, the descriptive phase of data analysis was entered. All themes that were presented in Appendix N were re-categorised and grouped into five major themes each containing several related minor themes. The major themes included a) communication, b) intervention, c) support systems, d) complementary and alternative medicine, and e) bioethical practice, and each contained minor themes such as the HCP's communication skills, speech-language pathology intervention, support groups, and decision-making. Following classification of these major themes the data was thus moved to a more abstract level, while still being founded upon the minor themes which were in fact comprised of the original data set. In re-categorising and classifying the themes into their major components however, much overlap between categories was evident. For example although the minor theme of warmth and compassion was reported under the major theme of support systems, it could have also been categorised under ethics. Figure 4 therefore provides a conceptualisation of the major themes established in this study, and depicts the overlap that exists between categories as well as the bi-directional influence that these have on the perceptions of the quality of MND management. Finally it should be noted that the specific results under each theme have not been reported because their basis lies in the preceding section (i.e. the participants'

perceptions of the medical and rehabilitative management of MND), and have therefore already been documented throughout this chapter.



**Figure 4:** Conceptualisation and Overlap of the Major Themes

## **CHAPTER FOUR**

### **DISCUSSION**

The main aim of this study was to investigate the perceptions of persons with MND and the perceptions of their family members with regard to the medical and rehabilitative management received on and following diagnosis. In relation to this aim the present chapter provides a discussion of the qualitative findings based on the interviews documented in chapter three. The discussion comprises three major components and includes a) an explanatory account of participants' perceptions, b) the implications of contextual variables, and c) a proposed new framework of ideal service delivery for all persons implicated in the management of MND.

#### **4.1 EXPLANATORY ACCOUNT OF PARTICIPANTS' PERCEPTIONS**

In accordance with the matrix based analytic approach that was used for data analysis in this study, data management and descriptive accounts were used to abstract the findings from the interviews into the five major themes of a) communication, b) intervention, c) support systems, d) complementary and alternative medicine, and e) bioethical practice. What follows therefore is the final phase of this analytic process, where explanatory accounts or plausible explanations of the study's findings are offered in relation to these major themes (Ritchie et al., 2003b). Little attention has however been given to discussing every result in isolation, because such a reductionistic approach breaks down information into its ultimate units (Evans, 2003), which in the case of this study would have resulted in mere simplicity and incompleteness of the overall meaning. Moreover the true value of the current study lies not in the significance of isolated findings, but rather in a summation of the results which can be applied to a much wider context (Lewis & Ritchie, 2003; Ritchie et al., 2003b).

##### **4.1.1 Communication**

Since poor patient-professional communication can affect the morale and psychological well-being of healthcare consumers, literature pertaining to health communication is dominated by information that addresses the abilities and skills of HCPs in this regard (Anstey, 1991; Arora, 2003). The difficulties that are faced by professionals when communicating with their patients, especially those with life-threatening conditions, is well documented along with the fact that HCPs are often

inept in meeting the communication and psychological needs of healthcare consumers (Anstey, 1991). In light of such literary reports that highlight the inadequacies of HCPs, the findings of the current study revealed however that the communication encounters associated with the management of persons with MND encompassed far more than mere communicative transactions made on the part of the professional alone. The role that the participants played in these encounters, as well as the impact of the communication impairment and the influence of environmental variables, also appeared to alter communicative interactions between healthcare consumers and HCPs. Moreover communication in this sense was found to include not only the linguistic and pragmatic styles of participants and HCPs that were influenced by the communication impairment, but also the content and manner of informational exchange that occurred as well as the questions and answers that transpired between the two parties. Finally a broader and more critical view of health communication in this study raised questions about patient-centred communication, and whether this concept has the capacity to move the management of MND towards a more patient-centred style of care.

#### **4.1.1.1 The Professional as a Communicator**

The most significant finding of this study with regard to the communication of professionals was that participants perceived medical and rehabilitative HCPs to be poor communicators. As a result some individuals believed that the poor communicative interactions between themselves and their HCPs had compromised the quality of the overall management that had been received. Reportedly dissatisfaction in terms of the communication of HCPs is not uncommon to the literature (Anstey, 1991; Ruiz-Moral et al., 2006; Tran, Haidet, Street, O'Malley, Martin & Ashton, 2004), and possibly also typical to other conditions besides MND. Thus by attempting to access and understand the explanations that underlie these perceptions, HCPs can perhaps begin to play a role in modifying and adapting negatively perceived communication behaviours and situations so as to pave the way for more positive communicative experiences between themselves and their healthcare consumers.

In terms of the specifics relating to the communication of HCPs, no significant findings were revealed with regard to speech and paralinguistics. Unless a particular

HCP presented with an overt communication impairment such as a stutter for example, no findings to the contrary were expected that might have resulted in communication breakdowns. With regard to non-linguistic communication the only remarkable finding occurred in Unit 2, where the person with MND reported feeling uneasy when the HCP failed to utilise eye contact. Eye contact and other nonverbal markers (e.g. tone of voice and body language) denote the amount of interest that a HCP has for his/her patient, as well as highlights the value that he/she places on the information and concerns provided by the healthcare consumer (Gallagher et al., 2005). In the absence of these behaviours the person with MND from Unit 2 possibly perceived the HCP to be distant, thereby making her feel uncomfortable during consultations. The ability of a professional to engage in non-linguistic communication during healthcare encounters is thus essential in order to reveal his/her emotions to the patient, reduce any emotional distress experienced by the healthcare consumer, as well as bring about improved patient satisfaction (Gallagher et al., 2005).

The fact that most participants were unable to comment on various non-linguistic behaviours such as proxemics, and some meta-linguistic behaviours such as adjustment of content, possibly leads one to assume that these dimensions of HCPs' communication abilities were unremarkable and therefore intact. While such assumptions are perhaps valid, findings of this nature could also suggest a limitation of the interview schedule that was used in this study. Various aspects of non-linguistics and meta-linguistics are perhaps so inherent to communication, that during communicative interactions all be they between patients and HCPs or between patients and any communicative partner for that matter, persons may fail to be aware of these seemingly insignificant yet highly informative components of communication. On this basis one might have therefore expected that participants would have been unable to answer questions that addressed the subtleties of communication. Furthermore given that poor non-linguistic communication by professionals can evoke emotional distress in patients (Gallagher et al., 2005), and that by nature MND is an emotionally distressing condition (Francis et al., 1999), even if participants had felt uneasy about inadequacies relating to non-linguistics and meta-linguistics, they may have failed to recognise this emotional arousal to be a result of poor health communication. Rather participants may have perceived their



emotions to be related to the distress inherent to MND. Consequently when one wishes to investigate the subtleties of communication that are not obvious to participants, observational measures may be more appropriate than the perceptual measures that were employed in this study. The design of the current study and the reliability of the data elicited may have therefore been enhanced by including an observational component over and above perceptual measures, whereby the communicative interactions between participants and HCPs could have been observed and analysed by the researcher. Notably while the original proposal for this study did intend to observe such interactions, because most persons with MND were not consulting HCPs on a regular basis at the time of data collection, observational measures between participants and HCPs were excluded in order to prevent jeopardising the entire pursuit of this study. Moreover whilst not discounting the richness of data yielded from observations (Grbich, 2003), perceptual measures nonetheless provide more valuable information about the subjective impact of patient-professional communication on patient outcomes, as well as the need for change (Arora, 2003).

Despite the components of speech, paralinguistics, and non-linguistics having little impact on the communication of HCPs, the perceptions of participants did reveal that the language used by professionals was of concern. The majority of participants perceived the use of long complex sentences and jargon by medical and rehabilitative HCPs to have impinged on their ability to understand the full meaning of MND. Reportedly the use of jargon in healthcare encounters often inhibits a patient's understanding of his/her disease and threatens him/her with the unknown (Skelton & Hobbs, 1999), and thus numerous articles have been written that encourage HCPs to avoid using medical terminology (Arora, 2003; Skelton & Hobbs, 1999). Similarly when communicating with persons with MND, Silani and Borasio (1999) state the importance of professionals providing information to patients in a manner that is clear and easy for them to understand, so as to reduce any emotional distress that might threaten their well-being. Interestingly however although the use of jargon by HCPs is a common assumption within the healthcare setting, this belief is not always true (Skelton & Hobbs, 1999). Following an investigation of 373 general healthcare consultations by Skelton and Hobbs (1999), no evidence was revealed that HCPs used medical jargon during communicative interactions with patients. Moreover it was

established that the language used by professionals actually diminished threats posed to patients and aided in providing them with reassurance about their condition. As a result it was thus suggested that if patients indicate that they have not understood their HCP, one needs to ascertain probable explanations for this poor understanding over and above the use of jargon (Skelton & Hobbs, 1999). On this basis given the contradictory reports that exist regarding the use of jargon by HCPs, for the sake of completeness in health communication literature there may be value in research that not only establishes the presence or absence of jargon as a compromising factor in healthcare interactions, but also possible explanations underlying the ability or inability of patients to comprehend medical content.

One possible explanation for persons with MND and their family members perceiving the use of long complex sentences and jargon as having an impact on their understanding of the disease, lies perhaps not in the communication abilities of professionals but rather in factors that are inherent to the participants themselves. Compromised understanding on the part of persons with MND and their family members may be the result of intrinsic coping mechanisms that are activated in such individuals so as to protect their emotional and psychological well-being. According to Folkman and Greer (2000), coping mechanisms include the thoughts and behaviours that a person utilises to regulate distress, manage the problem that is responsible for the distress, and maintain a positive well-being. Since MND is a chronic life-threatening condition that affects every aspect of a person's being and causes both the individual with the disease and his/her loved ones to have to cope with a changing sense of self, emotional and psychological distress is inevitable (Francis et al., 1999). In order to regulate such distress and protect the individual from any additional stressors, the body possibly enters a phase of "shut down" when it becomes too overwhelmed. Thus when HCPs provided participants with information that threatened to disrupt their emotional equilibrium, they possibly employed an escape-avoidance coping strategy which purposefully clouded their ability to attend to and process any overwhelming facts (Goldstein, Holland, Soteriou & Mellers, 2005). This strategy thereby offered them the opportunity to avoid consciously registering the stressful situation, and ultimately perceiving the language used by professionals as difficult to understand. Hence the emotions of anger, anxiety, and confusion that were reported by some participants when they were unable to understand the HCP,

were perhaps not a result of complex language and jargon per se', but rather an emotional state that had been triggered in an attempt to preserve a desirable well-being.

In the case of Unit 2 where the person with MND was a nurse, she too expressed that her understanding of the terminal illness that was threatening her life had been hindered by the HCP's use of complex language and jargon. Given this individual's profession and the fact that she would have better understood the use of medical terminology more than any other participant in this study, one may argue that the language and vocabulary used by the HCP must in fact have been problematic. However one may further argue that such a finding reinforces the power that coping mechanisms can have over one's functioning in times of distress. Moreover by virtue of this individual's prior knowledge, it is also likely that she had a more accurate insight regarding her future relative to the other participants. Since a self-regulation model proposes that persons use their prior knowledge and experiences to construct personal illness representations that in turn guide associated reactions (Sharpe & Curran, 2006), prior knowledge and experiences specific to this individual may have resulted in more overwhelming perceptions for her about the disease and her future compared to other participants. Patient coping mechanisms thus appear to be highly individualistic, with activation occurring based on each individual's specific illness representation and associated needs. On this basis while some HCPs may perhaps utilise long complex sentences and jargon, the conscious or sub-conscious activation of intrinsic mechanisms to protect individuals from the distress of MND is nonetheless a plausible explanation for the perceptions regarding the language utilised by medical and rehabilitative professionals.

Further to the difficulties reported in terms of language, the findings of this study also revealed concerns regarding certain aspects of meta-linguistics. For example in Unit 1 the HCP's awareness in terms of the need for turn-taking was perceived as poor because the professional was reportedly hasty in delivering information and failed to give the participants an opportunity to interject. Participants from this Unit also felt that the HCP was tangential when providing information, which in turn affected their understanding of the facts that had been provided to them. Furthermore these two participants believed that the HCP was unaware of the difficulties that they had

experienced in understanding the information that had been delivered, and that this sense of indifference had contributed to a detached healthcare consumer-professional relationship. Taken at face value these findings could suggest a HCP who is simply unconcerned about his/her patients and their needs. However in relation to the intrinsic coping mechanisms used by participants to protect themselves from the intensity of a terminal illness, HCPs may consciously or sub-consciously also adopt similar techniques in order to alleviate the emotional and psychological burden of engaging with chronically ill patients. Anecdotally one HCP reported to the researcher the immense anxiety and anguish that he experiences when having to engage with patients who have MND, knowing that despite what he tells them a bleak future still awaits the individual and his/her family. Although this psychological distancing cannot be generalised to all professionals involved in MND, behaviours such as haste during information delivery, tangential conversations, and a lack of awareness of a patient's needs may in fact be an attempt on the part of some HCPs to avoid close contact with patients and families. As a result, although the participants of this study felt that such behaviours had prevented an acceptable healthcare consumer-professional relationship from developing, for HCPs this may be the very type of relationship that they wish to avoid knowing that the death of a patient with a terminal illness is inevitable and that the healthcare consumer-professional relationship is therefore unsustainable. Furthermore by avoiding close contact with patients who are dying and by overlooking the emotional needs of these individuals, Anstey (1991) suggests that HCPs do not have to confront the threat of their own mortality and thus deal with the prospect of their own death.

With regard to the avoidance and/or haste of HCPs during communicative interactions, as well as the limited opportunities for participants to interject, it is possible that these behaviours may have also been indicative of the anxiety that some professionals might have experienced about either not being able to inform individuals fully about their future or not knowing an answer to a specific question. Although the general public has an omnipotent view of medicine and it is expected to be an exact science, questions such as, "*How long have I left to live?*" and "*What will my dying be like?*" cannot be answered with certainty (Anstey, 1991). HCPs may therefore engage in communicative avoidance, so as to escape situations where the potential exists for them to experience a sense of inadequacy, or be viewed upon by

healthcare consumers as lacking expertise. Thus while suggesting that the perceptions of participants regarding health communication are perhaps shaped in part by their own internal needs, it is evident that the communicative behaviours of HCPs that are perceived as cold and inappropriate may also be a function of the regulation and adaptation that they too must engage in to facilitate their own coping during emotionally distressing cases.

Beyond intrinsic coping mechanisms and the related communication skills of HCPs that function to distance both the patient and the professional from psychological distress, extrinsic variables are also likely to affect health communication. Reportedly one such variable that is influential in healthcare consumer-professional interactions is that of time. Given that professionals are constantly pressurised in terms of treating the maximum number of patients in the minimum amount of time, the physical requirements of patients often take priority over their emotional and communication needs (Anstey, 1991). Although Anstey (1991) believes it to be a myth that communication with patients takes a large amount of time, in the case of communication with communicatively impaired individuals it is in fact a rather time-consuming process. Moreover this process is likely to be hindered further when communicative partners (e.g. HCPs) are inexperienced in interacting with individuals who present with a communication impairment. A second extrinsic factor related to time is that of money, and the fact that for many HCPs their practice is a business (Cohen & Gabriel, 2002). Because “time is money”, some HCPs may avoid their communicatively impaired patients, knowing that the additional time needed to interact with these individuals could result in a loss of income. A final extrinsic factor that also has the capacity to affect communicative interactions with patients irrespective of their health condition, is that of HCP training (Anstey, 1991). According to Anstey (1991), training in the care of terminally ill patients especially with regard to communication and psychological aspects of care, is often poorly taught during the student years. As a result many professionals are often frightened when having to interact with a patient who is very ill and/or is dying because over and above biomedical demands, the HCP may feel ill-equipped to address the patient’s more psychologically or emotionally based needs. In the case of MND one might expect the fears of the HCP to be heightened even further because not only does he/she have to address the needs of a terminally ill individual, but also attending to

these needs when the patient is communicatively impaired is likely to make the situation more challenging. Participants' comments such as, "*Its simply easier and quicker to ignore her*", "*I am of no value to his business*", and "*They just don't know how to communicate with me*", highlight the role that these extrinsic variables appear to play in influencing the communication abilities of HCPs, and thus the perceptions of individuals in this regard.

Bearing in mind that a basic definition states that communication involves the transmitting and receiving of messages (Shames et al., 1998), beyond intrinsic and extrinsic variables health communication breakdowns may also arise simply as a result of questionable core communication skills. Some HCPs may experience difficulties with regard to fundamental health communication processes such as listening effectively, eliciting information through effective questioning, revealing the patient's perspective about his/her illness, expressing empathy, and including patients in healthcare consultations (Duffy et al., 2004). Furthermore because patients report dissatisfaction in terms of health communication and want better communicative interactions during healthcare encounters (Duffy et al., 2004), there appears to be a burgeoning of literature investigating health communication in an attempt to enhance the skills of HCPs (Stein, Frankel & Krupat, 2005). However beyond addressing fundamental communication skills, inadequacies in core health communication abilities are also likely to be exacerbated by the presence of a communication impairment. Findings from the present study indicated that the communication impairment influenced the communicative interactions that transpired between persons with MND and HCPs, thereby altering participants' perceptions of MND management. For example because most HCPs failed to direct communication to persons with MND and only conversed with family members, some participants perceived an inferior quality of healthcare. Whilst this behaviour on the part of these professionals may have been a technique to distance themselves psychologically from the terminally ill individuals, such communicative avoidance may have also occurred as a result of the fear that HCPs possibly experience due to uncertainty regarding how one should interact with a communicatively impaired patient. Moreover for this reason some HCPs may have avoided facilitating the communicative attempts of persons with MND and providing them with opportunities to convey their own opinions and preferences about their healthcare. However given that most

professionals might be uninformed and unskilled in terms of communicating with communicatively impaired individuals, such communicative behaviours are perhaps somewhat expected. Thus although the person with MND from Unit 1 for example, felt that the HCP was so disengaged from communicative interactions with her that he was unaware of any communication breakdowns or the need for conversational repair, the professional may have projected this attitude in an attempt to hide the fact that he was simply unaware of the correct steps that needed to be followed in order to restore effective communication. As a result the current study therefore highlights the need for research investigating core health communication skills to incorporate health communication in the context of communicatively impaired healthcare consumers.

Finally in the case of Unit 5 the person with MND reported that the HCP had acknowledged her communicative contributions and opinions, possibly because she had presented with relatively intact communication. Furthermore because she attended her healthcare appointments alone the HCP was forced to communicate with her, as no other communicative partners were available. Interesting results may therefore be yielded from future studies which investigate the dynamics of communicative interactions between HCPs and persons with MND who are communicatively impaired and attend healthcare consultations alone. More importantly it is likely that implications would arise from these studies in terms of communication training for HCPs. Although communication training for professionals such as physicians is not uncommon (Deveugele, Derese, de Maesschalck, Willems, van Driel & de Maeseneer, 2005; Duffy et al., 2004), limited attention has been given to the training of HCPs who treat communicatively impaired individuals. Kagan (1998a; 1998b) has however demonstrated that following communication training for HCPs who engage with persons with aphasia, dramatic improvements in healthcare consumer-professional interactions have been noted. These benefits possibly suggest that communication training for professionals who treat persons with MND could perhaps yield similar results. Moreover whilst one may argue that such effort is not feasible for a relatively uncommon condition, the skills that are taught to HCPs during training would not only apply to persons with MND, but could also be generalised to any communicatively compromised patient population that required such input. As a result such advances may begin to lay the

foundations for improving the skills of professionals as communicators, and thus modifying and adapting negatively perceived communication behaviours.

#### **4.1.1.2 The Person with MND as a Communicator**

In recognising certain inadequacies in the communication of HCPs, one is cautioned from assuming that it is the communication of professionals alone that has the capacity to compromise the quality of MND healthcare. Since communication is a bi-directional process that is dependent upon more than one individual (McLaughlin, 1998), the communication abilities of healthcare consumers are also likely to influence communicative interactions that occur between themselves and their HCPs. Consequently investigating the communicative abilities of healthcare consumers is as important as investigating those of HCPs.

According to Post et al. (2002), the manner in which patients communicate with HCPs is essential for successful healthcare encounters. However despite this importance various studies have revealed that some patients are in fact poor communicators within the healthcare arena (Parrot, 1994; Street, 1991). Reportedly patients typically voice their concerns in less than one fourth of medical encounters, and often describe symptoms indirectly through the use of clues (Korsch, Gozzi & Francis, 1968; Post et al., 2002). As a result in the case of the present study, it is possible that the reason some participants perceived HCPs to be detached and unaware of the needs of the person with MND, was because the input that they had provided to the professionals had been insufficient and delivered in an ineffective manner. Moreover because persons with MND seldom engaged in conversational repair due to the communication impairment, several occasions may have arisen where information provided to the HCP by the participant or vice versa, may have been misunderstood or lacking in clarity. No or futile attempts on the part of the person with MND to rectify these communication breakdowns may have therefore hindered professionals from fully understanding the needs of the person. In addition because most persons with MND seldom engaged in topic initiation, they may have failed to provide HCPs with personal concerns and opinions about their healthcare, also giving rise to the perception that professionals were indifferent to their needs. Thus given that some persons with MND may have been poor communicators premorbidly, and that in the presence of a communication impairment the situation is



likely to have been exacerbated further, it is plausible to suggest that the communication skills of individuals who are communicatively impaired need to be improved so as to achieve more effective healthcare encounters with their HCPs. Whilst respecting the fact that the communication impairment is likely to have posed significant challenges for persons with MND during healthcare consultations, and that these individuals may have felt embarrassed and uncomfortable during such encounters, one cannot expect a HCP to ask his/her patient every appropriate question to elicit all the relevant information that the patient wishes to discuss. Healthcare consumers also need to take responsibility for the giving and receiving of information during communicative interactions with professionals. The implications of this study in terms of the communication of persons with MND thus appears to be twofold: not only do healthcare consumers need to be made aware of their responsibilities within the healthcare encounter, but also persons who are communicatively impaired perhaps need to be empowered to play a more active role in their own healthcare (Funnel & Anderson, 2004; Ma, Warren, Phillips & Stanek, 2005).

In view of the need for healthcare consumers in general to become more proactive during consultations, the direct training of patients to improve their communication abilities has become more topical within the health communication literature (Post et al., 2002). The focus of this training is usually face-to-face and addresses skills such as active listening and eye contact (Post et al., 2002; Stewart et al., 2000). Whilst persons with MND might also benefit from this type of training, individuals who are communicatively impaired would perhaps derive greater value from communication training that moves beyond core communication skills and facilitates coping with the communication impairment. In view of taking more responsibility, persons with MND need to become more assertive and by so doing feel more confident to voice their concerns and opinions during healthcare encounters. Thus with the help of training to modify and refine one's abilities to convey messages more effectively as well as engage in processes such as conversational repair and topic initiation, communicatively impaired individuals can perhaps be taught to "own" their communication and feel comfortable in addressing HCPs regardless of how long this may take. Hence by providing communicatively impaired individuals with the correct techniques to facilitate their communication endeavours, and by encouraging them to believe that the messages that they wish to deliver are worthy of being heard, the

quality of patient-professional communicative interactions may be enhanced. After all the person with MND from Unit 4 who reported communicative success, may have perceived these positive experiences because he described himself as being persistent and believed that he had every right to communicate with his HCPs. Consequently in line with the bi-directionality of communication (McLaughlin, 1998), implications arise for research and the development of health communication training programmes that are suitable for enhancing the ability of both patients who are communicatively impaired, and professionals who are inexperienced and unskilled in such situations.

#### **4.1.1.3 Information Delivery**

In addition to the linguistic components that constitute communication, effective health communication also relies on the content of transactions and the manner in which information is transferred between healthcare consumers and HCPs. Apart from patients having a right to all medical information that will assist them in making informed decisions about diagnostic and therapeutic procedures (Bensing, 2000), many individuals also desire information about their medical condition and the appropriate treatment options (Leopold et al., 1996). Furthermore family members are also said to hunger for information about their loved one's health condition, and they often report the need for greater information, more timely information, and better coordinated information (Tilden et al., 1995). Thus in the presence of favourable information delivery, patient satisfaction in terms of the healthcare encounter is reported along with improved opportunities for partnership building between healthcare consumers and HCPs (Leopold et al., 1996).

In accordance with the perceptions of participants from this study, findings revealed a paucity of information provided by medical and rehabilitative HCPs. Both persons with MND and their family members reported that the quality and quantity of information rendered by professionals had been insufficient to guide them through the disease process. Information was believed to be inadequate in many regards, including facts about the nature of MND, the cause and progression of the disease, as well as the appropriate management options. Consistent with literary reports, this finding is not uncommon. Numerous studies have revealed that in general, healthcare consumers are often dissatisfied with the information that is provided to them by HCPs and they usually seek more detail about the nature of their condition, prognostic

factors and treatment options (Kiesler & Auerbach, 2005; Leopold et al., 1996; Tilden et al., 1995). Ironically however other studies have revealed that while patients report the need for large volumes of information regarding their health condition, in practice many persons shy away from medical facts and block the reception of information that is either difficult to handle or places them under threat (Hogbin & Fallowfield, 1989 as cited in Bensing, 2000; Kiesler & Auerbach, 2005; Waitzkin, 1985). On this basis there appears to be an incongruence between what some patients say they want in terms of healthcare information, and what they actually seek to redeem during consultations. In addition HCPs also need to respect individual variability (Miller et al., 1997; Miller et al., 2000), and the fact that while some patients may want to know all the details about their health condition, there are others who would prefer to know very little. There is thus a need for professionals to be alert to the signs that patients and their family members convey, as these cues signal how much information an individual is capable of receiving, processing, and assimilating during one consultation (Leigh et al., 2003).

In relation to the incongruence that is reported in terms of what patients say they want and what they actually seek during consultations (Kiesler & Auerbach, 2005), it is possible that information mismatch occurred in this study. Although most persons with MND and their family members reported a paucity of information provided by HCPs, it may be that during consultations adequate information was supplied but participants failed to acquire all the facts causing them to perceive an insufficiency in this regard. While one could also argue that the communication impairment may have prevented persons with MND from seeking additional information (e.g. about the etiology, prognosis and progression), the majority of informational transactions would have occurred around the time of the diagnosis, and for many participants their communication would have been adequate during this relatively early phase of the disease. It thus seems more likely that failure to process and assimilate information provided by HCPs was not the result of a communication impairment, but rather the result of previously discussed intrinsic coping mechanisms that functioned to protect healthcare consumers from potentially threatening situations or information. Just as some participants may have avoided processing complex language and jargon in order to regulate distress, some individuals may have either consciously or sub-consciously inhibited the assimilation of overwhelming facts in order to safeguard their emotional

well-being. Moreover the blocking of information was confirmed by some participants who stated that at the time of receiving information from HCPs they were so overwhelmed that they were unable to absorb all the details that had been provided.

Further to the intrinsic coping mechanisms that assist individuals in managing threatening information, empirical evidence indicates that the desire for medical detail is also dependent upon the severity of the disease. The more threatening a condition the more influence patients are prepared to grant professionals in terms of how much information to provide (Bradley, Zia & Hamilton, 1996). Since MND is a serious condition because it threatens an individual's functional integrity and presents impending disability and death (Schapira, 2003), one might have expected findings to the contrary in this study with participants being prepared to allow HCPs to control the information that was provided to them. However given the almost retrospective nature of this study because many participants were not consulting HCPs regularly at the time of the interview, they were required to think back to interactions with professionals. While thinking back to prior healthcare interactions, it is possible that for some participants their perceptions were influenced by their emotional state at the time of data collection. In other words these individuals perhaps felt less overwhelmed and more accepting of the disease at the time of the interview, and therefore believed that HCPs should have had less influence in directing the provision of information. However at the actual time of informational exchange with HCPs when participants were possibly feeling more vulnerable, they may have been satisfied with only that information that was provided to them. Consequently it is perhaps a limitation of this study that details about the medical and rehabilitative management of persons with MND were in part elicited in retrospect, as participants' opinions and perceptions are likely to have changed with different phases of the disease. Furthermore given that there is no "typical" MND patient (Gelinas, 1997), such explanatory accounts that are offered in terms of how persons might cope in times of vulnerability cannot be generalised to all persons with the disease. Gelinas (1997) reports that while some patients may be sophisticated with regard to their life experiences having overcome numerous emotional and/or physical demands to equip themselves to face the challenges of MND, others may have lead very sheltered lives and developed minimal psychological coping skills. To this end the need for management of persons with MND and their families to be individualised is therefore

further highlighted, and the fact that HCPs must be alert to the cues offered by patients in order to meet their unique needs at various stages in the disease process (Gelinas, 1997; Leigh et al., 2003).

Given the evidence of patient-specific factors to protect themselves from threatening situations, participants' perceptions relating to a paucity of information may have also arisen as a result of professional-specific factors. According to Gelinas (1999a) it is human nature for an individual to be reluctant about imparting bad news to another person, given the negative emotions and guilt that may subsequently arise. In the case of MND, because the type of information that is imparted is extremely negative in view of no offer for a cure and the patient's impending death, it is understandable why some HCPs might shy away from providing individuals with detailed information about the disease. Moreover because the prestige of the medical profession, especially for physicians lies in the ability to cure, some professionals may feel threatened by treating cases of MND knowing that they are unable to offer curative intervention (Conradi, 1999). Consequently by avoiding the provision of detailed information to a patient, HCPs are therefore offered an opportunity to protect their own vulnerability, escape having to face their own fears about death and/or dealing with the experience of personal loss, as well as prevent emotions of guilt (Anstey, 1991). On this basis whilst many participants perceived their HCPs to be unconcerned about their well-being, the seemingly detached behaviours of professionals were perhaps indicative of professional-specific or self-protective mechanisms that they had employed to protect themselves both mentally and emotionally from the reality of the situation.

In addition to self-protective mechanisms used by HCPs, practitioners in this study may have also employed patient-protective mechanisms in order to protect persons with MND and their family members from potential emotional harm arising from the delivery of threatening information. Some HCPs may have decided to withhold certain facts relating to MND, so as to protect participants from feeling overwhelmed or damaged. In such instances professionals reportedly perceive a need to employ "therapeutic privilege", whereby they use their power to conceal information from patients in the fear that too much detail may be too damaging or too painful for individuals to assimilate (Hunt, 1991; Pucci, Belardinelli, Borsetti & Giuliani, 2003).

Similarly because some HCPs believe that MND is a death sentence, they see no value in providing patients with too much detail about the condition. Out of compassion for persons with MND, such professionals therefore believe that it is acceptable to withhold information from them (Gelinias, 1999a). Contrary to this belief however, Bozcuk et al. (2002 as cited in Pucci et al., 2003) report that in patients with cancer there is no association between the disclosure of information and a worsening of quality of life or emotional functioning. Although uncertain as to whether the same phenomenon would occur in MND, this finding reported in relation to the cancer population possibly serves to caution MND practitioners from making their own decisions about the informational needs of their patients and respective family members. Rather each person with MND and his family should be treated on an individual basis, where the unique requirements of each healthcare consumer are established devoid of the professional's personal opinions and emotions (Gelinias, 1997).

Related to the provision of information and the content of transactions by HCPs, findings from this study revealed that at least one participant from each Unit valued the Internet as an additional source for acquiring knowledge. Reportedly information pertaining to health is one of the most sought after topics online, as it has the capacity to improve patients' understanding of their medical condition and their self-efficacy (McMullan, 2006; Sillence, Briggs, Harris & Fishwick, 2007). In a study conducted by McMullan (2006), multiple empirical studies were analysed to determine the use of the Internet for health information. Subsequently it was established that patients do not use the Internet as a replacement for the HCP, but rather as a means for confirming information that has been given and for gathering new facts. Contrary to this finding however, in the present study the Internet appeared to play a greater role than simply confirming the facts that had been provided by professionals. Given participants' perceptions regarding the paucity of information, some individuals relied on the Internet as their primary means for acquiring facts about MND. This technology therefore seemed to function as a replacement for the information that should have been provided by HCPs. Moreover given that previously discussed psychological mechanisms may have blocked the reception of information during consultations with professionals, some participants may have also relied on the Internet to acquire facts about the disease once they felt more able to process such

detail. Thus while McMullan's (2006) analysis comprised general medical conditions and oncology cases, one must acknowledge that such findings cannot necessarily be generalised to all clinical populations. Had McMullan (2006) studied only terminal diseases, the long-term nature and distress of such conditions may have resulted in the Internet being utilised as more of a primary source of information as noted in this study.

A further possibility for the Internet appearing to play a greater role in this study, is perhaps because most participants had either no or limited follow-up appointments with HCPs. Consequently individuals were only given one or two occasions in which to acquire as much information as possible from their practitioner. However according to Silani and Borasio (1999), information delivery for persons with MND should not occur during only one session because patients require time to process all the facts. Professionals therefore need to judge each individual's response to information provision and be prepared to stop the discussion at any moment during the consultation, with the intention of resuming information delivery at a future appointment. In addition HCPs also need to be prepared to repeat, review, and consolidate information on a regular basis, so as to diffuse any patient misunderstandings (Silani & Borasio, 1999). Had the participants of this study thus received follow-up appointments that allowed for on-going opportunities in terms of the provision and reinforcement of information, individuals may have perceived greater satisfaction in terms of information delivery and may have relied less on the Internet as a primary source of information.

Whilst recognising the importance of the Internet for some healthcare consumers, concerns of this technology as a primary means for gathering information also need to be addressed. The literature states that HCPs need to realise that information published online is not always accurate, and patients may make inappropriate self-diagnoses, demand new but unavailable or inappropriate treatments, and misinterpret some of the facts that are documented (McMullan, 2006; Sillence et al., 2007). Also because the majority of Internet users prefer to access more complex information and locate sites written for professionals, members of the public often fail to understand the information that they read and become lost in the complexity and amount of detail (McMullan, 2006). A further concern raised by the person with MND from Unit 5,

was that some sites may not be contextually appropriate for all patients who seek information online. For example the relevance of information and recommendations that are documented on sites created abroad, was queried in relation to its application to the South African healthcare consumer. On this basis if one thus considers these concerns in relation to the value that MND healthcare consumers appear to place on health information and the Internet, it is only fitting that HCPs ask themselves what role they should be playing in this relatively new area of healthcare?

In response to the preceding question and the fact that because the Internet has come of age it is unlikely that healthcare consumers can be stopped from seeking medical information online, it is perhaps time for HCPs to make more effective use of this technology to complement the healthcare services that they render. According to McMullan (2006) the value of the Internet lies in the fact that not only is it a major source of health information, but it also empowers patients to make decisions and communicate with their HCPs. Thus in relation to the theoretical perspective adopted for this study, the Internet has the capacity to achieve more patient-centred care because it shifts the role of patients from passive recipients to active healthcare consumers (McMullan, 2006). Such benefits might therefore have a positive spin-off in terms of the MND population. Given that healthcare consumers of MND management appear to make plentiful use of the Internet, professionals might use this finding to their advantage in order to optimise the management process and achieve more patient-centred care. However more than just promoting the Internet to access information pertaining to MND, HCPs need to ensure the availability and integrity of informational sites (McMullan, 2006). Hence to meet the ideals of patient-centred care, MND professionals should be familiar with the information that is online, know where to access the data so that patients can be guided to the appropriate sites, and collaborate with healthcare consumers in terms of analysing the information and making sound management decisions (McMullan, 2006). Furthermore for South African HCPs additional implications arise. Perhaps these professionals need to be more proactive in creating South African-specific sites that are not only appropriate for the current healthcare consumer-base, but also give these healthcare consumers a better sense that local HCPs are committed to the management of MND. Moreover such projects may also facilitate networking and improved collaboration between



professionals, which in itself might contribute to improved treatment and hence more positive perceptions in terms of the management of MND.

According to Schapira (2003), the manner in which information is delivered to patients also affects the way in which they adapt to chronic illness. When information is imparted with sensitivity, patients often find inner strength and coping mechanisms that will assist them through the disease trajectory. However when news is delivered bluntly or without allowing patients to express their concerns, they may be left feeling bewildered, afraid, or angry, and may even begin experiencing depression at a later stage in the disease (Schapira, 2003). Findings from the present study revealed that HCPs imparted information in a manner that was perceived as callous and damaging to both persons with MND and their family members. In contrast Leigh et al. (2003) suggest that information delivery for persons with MND should be honest, sensitive and frank, but not brutal. However given the emotional vulnerability that appears to confront persons with MND and their family members, it is possible that being honest and frank in this study may have been perceived by participants as being callous and brutal because of their emotions. Moreover the emotions of HCPs may have also altered the appropriate manner in which they should engage in information exchange. For example in the case of those professionals struggling to cope with their own mortality, the amount of information that they provided may have been reduced and imparted in a seemingly insensitive manner, thereby giving rise to participants' reports of dissatisfaction in terms of the quality, quantity, and manner of information delivery.

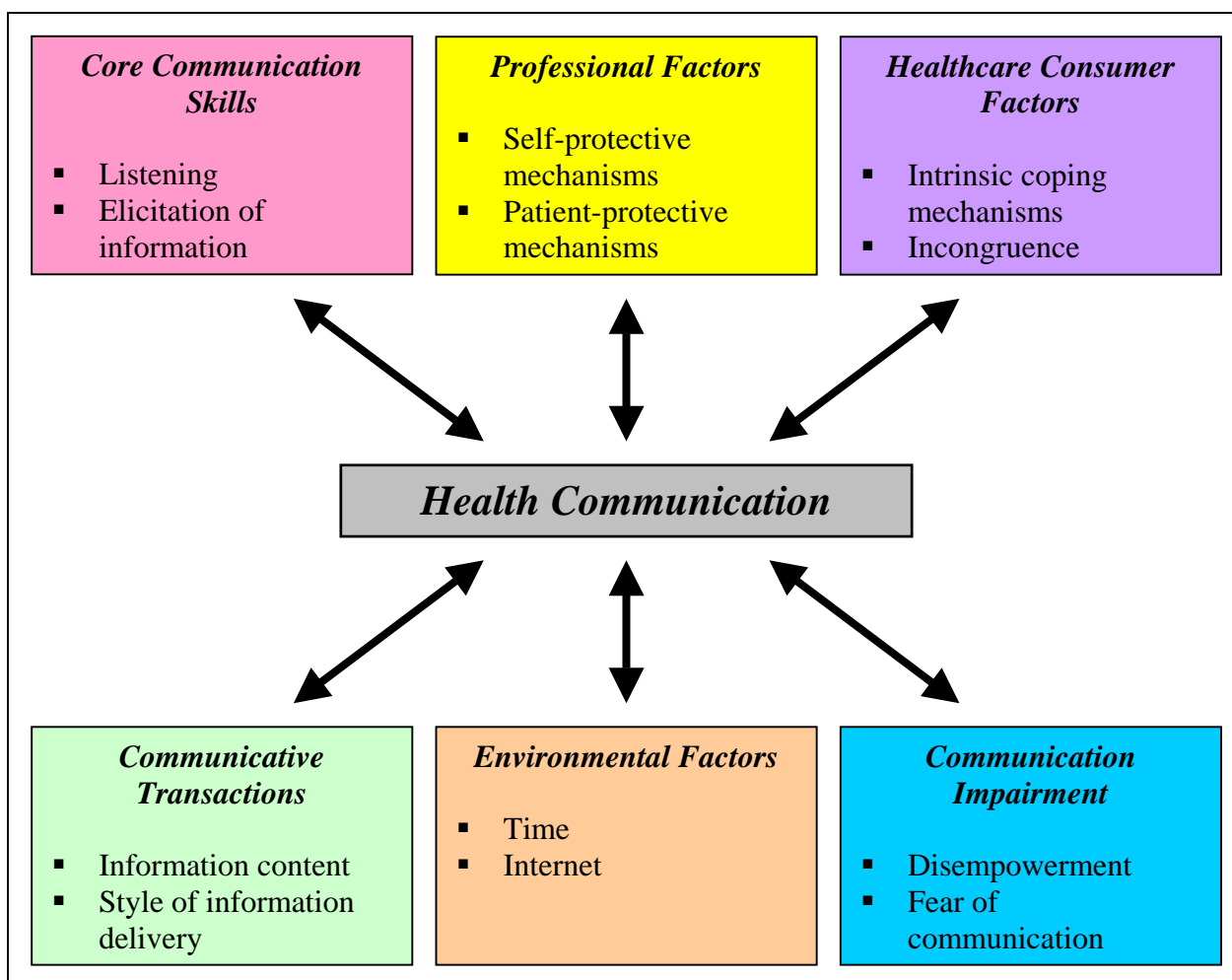
A final means of achieving information exchange in healthcare encounters is for both healthcare consumers and HCPs to ask questions. Offering patients time to ask questions is essential to the process of information delivery, as it not only provides an opportunity for improved knowledge but also provides patients with a sense of empathy and support (Leigh et al., 2003; Silani & Borasio, 1999). In the present study participants reported that although family members engaged in this behaviour, persons with MND seldom asked their HCPs questions because of the difficulties imposed by the communication impairment. Moreover for those family members who did ask questions, many of them had to initiate this type of communication themselves because HCPs did not offer such opportunities spontaneously. In view of

these limited opportunities to ask questions, one might therefore agree that information exchange for these participants was in line with a paternalistic model. There appeared to be a one way flow of information, where the HCP provided the facts that he/she deemed important and the patient was a passive recipient of whatever amount and type of information the professional chose to reveal. This model of information delivery is however in contrast to a shared decision-making model, where information exchange is a two way process such that at a minimum the HCP provides all information that is relevant to making decisions, while the patient provides information regarding his/her values, preferences, beliefs and knowledge about the illness (Charles, Gafni & Whelan, 1999). In acknowledging that a two way process of information exchange is perhaps the ideal, it is possible that the communication impairment resulted in the exchange of information in this study to be labelled as paternalistic in nature. Thus not only might persons with MND have avoided asking questions in view of their communication difficulties, but also HCPs possibly avoided placing participants and themselves in potentially embarrassing or uncomfortable situations by providing opportunities for questions. In view of this argument two issues therefore arise. Firstly as mentioned previously, persons with MND need to be empowered to play a more active role in their healthcare by making known their questions and opinions. Secondly HCPs on the other hand, need to be trained and taught to facilitate the communicative attempts of persons who are communicatively impaired. Moreover although one may argue that the asking of questions is only a small part of the healthcare encounter and is possibly not worthy of research and training efforts, Maguire (2000) states that if patient concerns remain undisclosed they may cope less well with their illness and be at greater risk for developing high levels of emotional distress and even clinical anxiety and/or depression.

#### **4.1.1.4 Implications of Participants' Perceptions**

On the basis of the discussion thus far, it is therefore evident that health communication for the management of MND is a complex enterprise. Figure 5 demonstrates the numerous intrinsic and extrinsic factors which may influence health communication and account for the compromised perceptions that were elicited from the participants of this study. Although it is difficult to pinpoint any one reason why HCPs were perceived as poor communicators, or why communication between persons with MND and professionals was deemed inadequate, the communication

impairment evidently contributed a significant dynamic to the complexity of health communication. Since participants perceived the communication impairment to be a compromising variable both in terms of patient communication and HCP communication, it is perhaps the case that professionals are not so much poor communicators as they are unskilled in engaging with communicatively impaired individuals. Also it is likely that persons with MND are themselves unskilled in achieving effective communicative interactions in the healthcare arena. On this basis implications therefore arise in terms of intervening at this level of healthcare. However unlike other influencing variables (e.g. non-linguistics) that are documented in the literature and specify means for improving the communication skills of HCPs in general (Anstey, 1991), health communication in the presence of a communication impairment has received limited attention. Also whilst much of the literature focuses on addressing isolated core health communication skills, this approach is perhaps questionable in the present study because in essence health communication that centres around the management of MND is a multifaceted and dynamic process. Hence understanding this area of practice and intervening at this level of healthcare is likely to require a more multifaceted and dynamic approach than simply training isolated communication skills. Consequently in attempting to comprehend the depth and complexity of health communication for the management of MND, researchers perhaps need to move beyond the mere formulation of plausible explanations for various communication behaviours, and begin translating research findings into practice as well as operationalising theories of communication. Such practical advances may bring about more meaningful changes in the realm of health communication especially for communicatively impaired individuals, such that the management of MND is perceived as more satisfactory for these healthcare consumers.



**Figure 5: Factors Influencing Health Communication**

#### 4.1.1.5 Health Communication From a Broader Perspective

In attempting to translate participants' perceptions of health communication into practice, one needs to consider the findings of this study in relation to the theoretical perspectives discussed in chapter one. Healthcare that is congruent with healthcare consumers' opinions and is patient-centred is achieved through patient-centred communication, or a way of communicating with patients in a manner that considers their personal perspective, acknowledges their psychosocial context, understands their view of the health condition, and shares power and responsibility (Epstein et al., 2005). In accordance with this definition however, HCP communication behaviours perceived in this study did not appear to be indicative of a patient-centred communication style. The majority of participants felt that few HCPs had elicited and

understood the perceptions and opinions of the person with MND, and few had considered the person from the context of his/her communication impairment. In addition perceptions elicited from participants revealed that there was a disproportionate share of power and responsibility, with the person with MND having little control over choices and decisions that needed to be made about his/her future. However before making claims about patient-centred communication and suggesting that this style of communication was not apparent in the present study, one perhaps needs to first take a more in-depth look at the meaning of this construct. Although Epstein et al. (2005) provide a detailed definition of patient-centred communication (described in chapter one), which appears desirable in that it strives towards achieving the ideals of quality healthcare, a more critical view of the concept reveals that it is a mere philosophy of care with no practical guidelines as to how one should implement a patient-centred style of communication. Also although the patient's perspective, the psychosocial context, sharing understanding, and shared power and responsibility constitute patient-centred communication (Epstein et al., 2005), in order to achieve any of these components communication between the healthcare consumer and the HCP must transpire. Ironically however the literature does not specify what exactly must occur during such communicative interactions, or how the healthcare consumer and the professional must engage in healthcare transactions, in order to meet the requirements that give rise to a patient-centred style of communication. Moreover in view of a paternalistic attitude, one might question whether some HCPs know how to share power and responsibility within the healthcare encounter, given that equality in patient-practitioner relationships has not been the trend in healthcare. In the case of this study, it is also questionable how the HCP might elicit the perspective of the patient if he/she feels anxious or is unfamiliar with communicating with an individual who is communicatively impaired. Consequently although the concept of patient-centred communication is an ideal in the sense that theoretically it places the patient at the centre of the healthcare encounter, and empirical evidence supports the fact that the majority of healthcare consumers desire healthcare interactions that consider their perspective, offer them autonomy, and acknowledge their unique context (Little et al., 2001), the literature seems to fall short of providing practical solutions for engaging this style of communication and achieving the ideals of this philosophy that bring about patient-centred care.

A further look at the construct of patient-centred communication also reveals that although its goal is to facilitate the HCP in providing care that is concordant with a patient's values and preferences (Fossum & Arborelius, 2004), no mention is made of the healthcare consumer's communication behaviours that may influence the process. Given the bi-directionality of communication however (McLaughlin, 1998), a theory-based definition of patient-centred communication may be more comprehensive if the communication behaviours of patients that either influence or are influenced by patient-centred care are also considered. Epstein (2000) states that because one HCP may be more patient-centred with some patients than others, patients possibly have the capacity to induce patient-centredness in professionals. If so, then it is possible that patient-centred communication might also be induced by patients, such that some patients may cause HCPs to engage in more of a patient-centred style of communication than others. For example a patient's emotional status or communication impairment may influence the style of communication that the HCP chooses to adopt throughout the healthcare encounter, thereby affecting the degree to which the HCP feels comfortable in eliciting the healthcare consumer's perspective, understanding the psychosocial context, sharing understanding, and sharing power and responsibility. Thus rather than a mere deficiency perceived in terms of HCPs' communication abilities, it is possible that the communication behaviours of participants and most likely the communication impairment, also contributed to this perception. Consequently the concept of patient-centred communication may be better grounded theoretically if the bi-directionality of communication is considered by focusing on the communicative behaviours of both HCPs and patients. After all, despite patient-centred communication being recognised as a central tenet to high-quality healthcare (Epstein et al., 2005), the present study has demonstrated that health communication and healthcare in general cannot be understood in its entirety without acknowledging the contributions that both patient and HCP bring to the healthcare encounter. Moreover since it is the patient who is the ultimate arbiter of patient-centred care (Epstein, 2000), it seems apt that a philosophy of care which is indorsed to meet the needs of patients, not only facilitates the HCP in this regard but also includes the healthcare consumer.

On the basis of such a brief yet critical analysis of patient-centred communication, it is thus evident that a lack of clarity surrounds the construct especially in terms of

operationalisation. In addition the operationalisation of patient-centred communication is made more difficult by the presence of a communication impairment. However despite both practical and theoretical concerns relating to patient-centred communication, the ideals of this construct and the ideals of patient-centred care have nonetheless had a positive impact on moving healthcare further away from a medical model of practice, and striving towards a higher quality of care that views the patient holistically. Thus rather than abandoning the construct of patient-centred communication because of its inadequacies, Epstein et al. (2005) suggest that researchers engage more actively in studies which aim to define a more coherent theory that is empirically testable and verifiable. Furthermore although this study demonstrated that the ideals of patient-centred communication were not apparent in healthcare encounters between persons who were communicatively impaired and HCPs, it is acknowledged that patient-centred communication is a relatively new construct that is as yet perhaps not well enough refined to include health communication in the context of a communication impairment. However given the need for equality in service delivery (Ross & Deverell, 2004c), persons who are communicatively impaired also warrant healthcare that meets the ideals of patient-centred care and patient-centred communication. As a result researchers are perhaps called to draw on the principles of this construct in order to refine and adapt them so as to produce a more coherent theory that is applicable to communicatively impaired healthcare consumers.

With respect to the fact that patient-centred communication thus has no practical guidelines for implementation and does not account for the bi-directionality of communication or a communication impairment, the concept needs to be revisited in terms of these variables. Furthermore because this study has revealed that persons who are communicatively impaired need to be empowered to take responsibility for their own communication, and many HCPs are perhaps unskilled in this area of practice, the need for communication skills training is reiterated for both patients and professionals. However because most of the general health communication literature appears to be dominated by information that addresses the assessment of HCPs' communication skills, it is perhaps time that researchers and clinicians focus more on practical training that will facilitate professionals in achieving a better patient-centred style of communication. Practical training is also indicated given that some HCPs are

poor communicators because they are often uncertain of what aspects of their behaviour will result in therapeutic change (Ruiz-Moral et al., 2006; Squier, 1990 as cited in Arora, 2003). Moreover for HCPs who interact with communicatively impaired patients, practical training is possibly even more essential because the requirements for these professionals are likely to be vague given that such patients are treated less often than their communicatively intact counterparts. In addition because patients are often ineffective communicators themselves, and for the most part healthcare consumer-professional communication is addressed by focusing on the skills of HCPs, the direct training of patients in terms of their communication skills is a new yet welcomed advancement to the field of health communication (Post et al., 2002). Particularly for persons with MND, direct patient training may be one of the most beneficial ways for individuals to learn not only how to manage their communication impairment in general, but also how to achieve more effective communicative interactions during healthcare encounters. Consequently since both persons with MND and HCPs in this study were hindered from successful communicative interactions especially in the presence of the communication impairment, and effective communication is essential for quality healthcare encounters (Teutsch, 2003), it must be recognised that the speech-language pathologist plays a vital role in terms of patient-centred communication from the perspective of the communication impairment. Specifically speech-language pathologists occupy a unique position in that by combining their knowledge of communication pathology with that of health communication, they may be able to develop more comprehensive communication theories and training programmes that might benefit both patients who are communicatively impaired and their HCPs.

Possibly one of the most valuable contributions that speech-language pathologists could make towards patient-centred communication in the context of a communication impairment, is to address this construct of health communication in terms of a social model of disability. According to a social model, disability stems from the fact that an individual's social and physical environment is unable to accommodate his/her unique needs, and thus the experience of disability is not only a consequence of the impairment inherent to the individual but also the disabling barriers and attitudes imposed by society (Pound, Parr, Lindsay & Woolf, 2006; Simmons-Mackie, 2001). Within the domain of speech-language pathology, social



approaches to intervention are widely discussed in the aphasiology literature. Specifically with a long-term condition like aphasia, a social approach to intervention has been viewed with optimism because it promotes membership in a communicating society and enhances participation in activities that are relevant to the individual (Simmons-Mackie, 2001). The advent of a social approach in healthcare has therefore shifted practice away from a traditional model of intervention, with patients now being empowered to engage in a participatory role (Kagan, 1998b; Simmons-Mackie, 2001). Rather than merely accepting prescriptions made by professionals, patients are encouraged to collaborate with their HCPs in order to establish ways of living with their illness in the presence of internal problems and external barriers (Marshall, 1998; Simmons-Mackie, 2001). In addition for persons with such long-term conditions the focus of intervention is no longer on illness but also on health (Kagan, 1998b; Simmons-Mackie, 2001).

With respect to the advantages mentioned in the above paragraph, it thus becomes evident that similarities exist in terms of the principles that underlie both a social approach to intervention and patient-centred communication. For example just as a social approach highlights the importance of patients participating in decisions made about their healthcare (Simmons-Mackie, 2001), patient-centred communication is based on healthcare consumers sharing power and responsibility within the healthcare encounter (Epstein et al., 2005). Thus given that in the present study persons with MND lacked participatory control in their own healthcare, and MND and aphasia are similar in the sense that both conditions are characterised by a long-term communication impairment, it is possible that health communication and the management of this disease may be enhanced by drawing on the principles that underlie a social approach to aphasia intervention. By promoting membership in a communicating society and enhancing participation in personally relevant activities (Simmons-Mackie, 2001), persons with MND may be facilitated in not only engaging more fully in their daily communicative routines, but also in playing a greater role in their healthcare routines. In addition because the perceived unsatisfactory healthcare encounters evident in this study were not a result of patient or HCP factors alone, but rather an interaction between factors inherent to members of the Unit and the environment, by addressing external barriers (e.g. the communication skills of communicative partners) over and above internal problems (i.e. the communication

impairment), persons with MND may be facilitated further in becoming more of a participant in their own life. If speech-language pathologists therefore adopt a social approach to the management of MND, members of the Unit can be trained to achieve more collaborative and satisfactory healthcare encounters that not only meet the ideals of a social model of intervention, but in doing so also bring about a more patient-centred style of communication.

One social approach that could be applied to the management of MND is that of “Supported Conversation for Adults with Aphasia”. By adopting this approach and modifying it to meet the needs of persons with MND, these individuals might be afforded the opportunity to participate in a communicating society (Kagan, 1998b) as well as be encouraged and facilitated to interact with their HCPs and discuss their healthcare agenda. Furthermore because an approach such as “Supported Conversation for Adults with Aphasia” centres on the training of conversational partners (Kagan, 1998b), HCPs involved in the management of MND can be equipped with the appropriate methods, resources, and skills to achieve effective health communication between themselves and their communicatively impaired patients. In return such efforts would function to not only reveal the competence of the person with MND, but also reduce the psychosocial consequences of the communication impairment and allow the individual to experience success and a sense of competency regarding his/her communicative abilities (Kagan, 1998b; Simmons-Mackie, 2001). Moreover the person with MND might also be empowered to take responsibility for his/her own communication. A social approach to the management of MND thus covers multiple purposes in that not only does it account for the communication impairment, function as a practical tool to improve communicative access, and address the bi-directionality of communication, but it is also anticipated that more satisfactory healthcare encounters may be experienced by all members of the MND Unit. Therefore despite further research required in this area, by adopting the principles of a social approach, health communication for the management of MND may be brought one step closer to the ideals of patient-centred communication in the context of a communication impairment.

Finally whilst suggesting a social approach to address health communication in relation to the management of MND, the researcher acknowledges that such a

recommendation has been considered superficially and is by no means a comprehensive solution to this complex situation. However given the paucity of literature that exists in terms of health communication for persons with MND, this study has made an attempt to begin operationalising patient-centred communication in the presence of communicatively impaired healthcare consumers. Moreover in view of the societal barriers inherent to the South African context, further research is required for adopting a social approach for the management of MND and refining it to ensure patient-specific and context-specific suitability. Also a responsibility lies with speech-language pathologists to create an infrastructure of communication for communicatively impaired healthcare consumers, as well as train HCPs and conversational partners in general to achieve competency during communicative interactions (Kagan, 1998b). Just as issues such as physical access must have looked equally insurmountable in past decades for people with physical disabilities, Kagan (1998b) believes that although communicative access is more challenging because it is difficult to see and understand, the possibility for development in the area does exist provided the initial goals are realistic.

In conclusion it is clear that while the majority of participants perceived dissatisfaction in terms of health communication, the management of MND is characterised by a complex web of communicative interactions that transpire between members of the Unit. The intricacy of such transactions is shaped by a multitude of variables that arise from both healthcare consumers and HCPs, as well as the fact that the communication impairment contributes a further confounding dynamic. However rather than trying to establish what goes wrong during healthcare encounters and blaming various individuals for their poor communicative skills, researchers and clinicians particularly those in the field of speech-language pathology, might better focus on guiding and empowering members of the Unit to utilise more effective health communication and become more aware of the communicative needs of their conversational partners. Hence Epstein (2006) recommends that because the flaws and inadequacies of present-day health communication are common knowledge, rather than focusing on a deficiency model it is time to look at synergy or how the establishment of one goal can facilitate the achievement of others. Consequently one way to operationalise theories of communication and achieve theoretical ideals that are documented in the literature, is to address the multifaceted nature of health

communication for the management of MND from a social perspective. By considering the bi-directionality of communication, the communication impairment, and the practicalities of achieving adequate health communication, patient-centred communication from within a social model may best equip HCPs to move the management of MND towards a more patient-centred style of care. And thus researchers and clinicians are urged to view the challenge of health communication in the context of a communication impairment with earnest, because not only are persons with MND competent adults in all other regards, but also these individuals are surely as deserving of effective health communication as their non communicatively impaired counterparts?

#### **4.1.2 Intervention**

Until recently the outlook for persons diagnosed with MND has not been viewed in a positive light because of the absence of curative interventions. However with greater acceptance of this fact and an improved understanding of the pathogenesis of MND, new therapeutic agents have become available for treatment purposes, and advances have been made in the management of symptoms associated with the disease (Miller et al., 1997). Notwithstanding the role of disease-specific interventions, significant emphasis is now being placed on patient-specific approaches that function to enhance the patient's quality of life, maintain patient comfort throughout the disease trajectory, and concurrently mitigate the complications of MND (Sufit, 1997). The management of this disease thus comprises a broad spectrum of care, covering the initial consultation, the diagnosis, helping the patient make decisions about symptom management, dealing with end-of-life issues, and possibly even being present at the memorial service (Miller et al., 1997). Furthermore in order to attend to the myriad of symptoms common to MND as well as meet the medical and rehabilitative needs of patients, the skills of a variety of HCPs must be employed from within a well coordinated team approach (Francis et al., 1999). However despite these advances in the management of MND that have been documented in the literature and implemented abroad, the results of the current study revealed questionable findings in terms of the intervention trends specific to the participants in this research project. Although by no means a representative study of the management received by all persons with MND in South Africa, concerns were nonetheless raised with regard to the fact that referrals for rehabilitation and in particular speech language pathology

intervention (given the communication impairment), were not a central component of each individual's management regime. Hence attention to the multifaceted nature of MND was not apparent in this study, along with the fact that a team approach was clearly absent in the coordination of each Unit. In addition participants also perceived dissatisfaction in the management that had been received, describing intervention efforts for MND as feeble and inferior compared to other disorders such as Multiple Sclerosis and cancer. As a result such findings raise questions as to why substandards appear to exist in terms of the management of MND, and whether consideration of international guidelines has the capacity to achieve more of a comprehensive and coordinated approach to MND intervention efforts.

#### **4.1.2.1 Speech-Language Pathology Intervention**

Given the perspective adopted for this study, one of the most concerning findings was the fact that the majority of persons with MND were either uninvolved in speech-language pathology intervention at the time of data collection, or had never consulted a speech-language pathologist following diagnosis of the disease. Furthermore for the individual from Unit 1 who did attend speech-language pathology intervention, negative experiences were perceived. Reportedly this person with MND was informed that nothing could be done for her communication impairment which would become progressively worse, and no mention was made of the potential for swallowing difficulties or the plan of action that should be implemented under such conditions. A closer look at the results of this study also revealed that all persons with MND who did attend speech-language pathology intervention, were not referred by another HCP or referring agent. Rather the two individuals for example who were receiving ongoing speech-language pathology, had instead sought therapists of their own accord. After having consulted several speech-language pathologists who expressed their inexperience or lack of knowledge regarding MND, both individuals managed to locate a therapist who worked in the field of neurodegenerative conditions. On the basis of the results of this study two major issues are therefore apparent with regard to speech-language pathology intervention for persons with MND. Firstly speech-language pathologists appear to be omitted from the referral network, such that persons with MND are not referred to the appropriate HCP in order to receive speech-language pathology intervention. Consequently individuals either fail to attend speech-language pathology at all, or they waste a significant amount of

their time and money trying to locate an appropriate therapist. Secondly some speech-language pathologists seem to be unfamiliar with treating persons who have MND, and possibly even assume that the profession plays no role in managing this patient population. As a result the potential is created for healthcare consumers to either receive inappropriate intervention or inappropriate recommendations regarding the value of speech-language pathology.

Contrary to international reports supporting the speech-language pathologist as an important member of the MND team (Francis et al., 1999; Leigh et al., 2003), a review of the literature at the time of this study did not reveal any speech-language-pathology-generated documents or position statements that define explicitly the role of the profession in managing MND and participating in the team. Hence an international need arises for therapists to formalise and document their role in this area of practice, so that other HCPs can become aware of the exact knowledge and skills that speech-language pathologists bring to the MND team. However based on the results of this study, before focusing on defining the speech-language pathologist's role in the management of MND, it may be of greater importance to first consider the reasons for inadequate referrals and the unfamiliarity of therapists in terms of treating persons with MND. The fact that the referral of persons with MND for speech-language pathology intervention appeared problematic, is possibly related to a mere lack of involvement or a lack of willingness of some therapists to treat this patient population, thereby resulting in unfamiliarity with the disease. Just as Thompson and Playford (2001) report the lack of involvement of speech-language pathologists in the area of Parkinson's disease despite the literature supporting their role in many neurodegenerative conditions, so too may be the case in the management of MND. If one considers an example from Unit 2, the recommendation for a percutaneous endoscopic gastrostomy was made by a representative of the MND Association of South Africa in conjunction with a consulting physician. At no stage during this process was a referral made to a speech-language pathologist, despite the management of dysphagia falling partly within the domain of speech-language pathology intervention (Leigh et al., 2003). While some speech-language pathologists may therefore be hasty to criticise various members of the MND team for stepping on their turf, one must consider the possibility that a lack of involvement or willingness on the part of this profession to treat persons with MND, may have prompted other

HCPs to cross clinical boundaries in this instance in order to act in the best interest of the patient. On this basis if a lack of involvement or willingness to engage in the management of MND is the reason for speech-language pathologists' unfamiliarity with the disease and omission from the referral network, then this occurrence needs to be understood in an attempt to bring about more acceptable speech-language pathology experiences.

With regard to the limited involvement of speech-language pathologists in the area of MND, no literature could be found that provides an explanation for this phenomenon. An experienced speech-language pathologist who participated in the focus group, did however report anecdotal evidence indicating that some therapists are reluctant to work in the area of neurodegenerative conditions because of the difficulties and challenges inherent to this patient population. The severity of the physical and communicative impairment along with the emotional nature of the disorder and impending death, reportedly places too great a demand on certain therapists. Similarly Baider and Wein (2001) report that in the oncology arena, HCPs often want to "run away" from the overwhelming vulnerability and psychological distress that they experience in relation to a patient's anticipated death. Understandably some speech-language pathologists are therefore more content to practise in other areas of speech-language pathology, where the emotional burden and clinical requirements may not be as intense as those relating to the treatment of various neurodegenerative conditions. Ironically in considering the treatment of MND however, although the illness itself is a relatively uncommon disease, the resulting dysarthria and dysphagia are nonetheless impairments common to many clinical populations that speech-language pathologists oversee. Hence by drawing on the basic principles that apply to the treatment of a mixed spastic-flaccid dysarthria, as well as utilising one's skills to implement alternate and augmentative communication and manage dysphagia, the management of MND in fact need not be viewed as overly difficult. However in respecting that some speech-language pathologists may find the overall physical and emotional presentation of MND too distressing, as well as the fact that clinicians are unique individuals with different interests, it is understandable that not all therapists will feel equipped and competent to treat persons with this condition. Also from an ethical standpoint it is acknowledged that if a therapist is not prepared theoretically, clinically, and emotionally to treat a person with MND, then for the sake of the

patient it is imperative that the speech-language pathologist withholds services. Thus in order to ensure that persons with MND receive only high standards of care that meet patient approval, the possibility that only a small group of speech-language pathologists exists who can intervene appropriately in the area of MND is acceptable. After all Johnson and Jacobson (1998a) stress that high standards of service delivery only occur when clinicians perform within their clinical boundaries and areas of competency, and act in the best interest of the patient. In the event of clinical uncertainty however, because all speech-language pathologists possess a broad base of knowledge regarding the pathophysiology of communication and swallowing disorders (Johnson & Jacobson, 1998a), at a minimum they should draw on their basic clinical knowledge and intuition to guide their judgments for making appropriate recommendations about speech-language pathology intervention or referral to a suitable colleague. Given that communication is the foundation for human freedom (Horner-Catt, 1999 as cited in Sarno, 2004), failure of speech-language pathologists to provide communicatively impaired persons with a system of communication or a referral to a colleague, not only violates these healthcare consumers' human rights and influences their healthcare in a negative manner, but also portrays the profession as generally inefficient and ineffective.

While a need exists for speech-language pathologists to enlarge their involvement, knowledge, and experience in terms of MND, in attempting to do so some professionals have perhaps come up against barriers. For example the challenge of securing funding for a terminal illness that requires long-term intervention (Rotstein, Hazan, Barak & Achiron, 2006) has possibly hampered the involvement of some professionals in this area of practice, thereby preventing them from establishing a clinical identity with healthcare consumers and other HCPs who comprise the MND Unit. By virtue of this lack of clinical identity, some healthcare consumers and HCPs associated with this study may have therefore failed to realise the value of speech-language pathologists in the management of MND. Consequently speech-language pathologists interested in this area of practice and neurodegenerative conditions in general, possibly need to work towards first creating a clinical identity in the mind of the public, as Johnson and Jacobson (1998b) claim that a clinical identity strengthens a profession's clinical position. Whilst this challenge is not necessarily an easy one for clinicians to undertake, literature used to guide medical speech-language



pathologists in achieving their own clinical identity may be of value to speech-language pathologists involved in the management of MND, given that both professional subgroups appear to be challenged by similar difficulties. Although the field of speech-language pathology has in general had a fair amount of recognition from the public, Johnson and Jacobson (1998b) state the difficulty that medical speech-language pathologists have had in achieving an identity different from that of the therapists who work in school settings. Not only has this speciality had to compete for funding, medical speech-language pathologists have also had to demonstrate their value in a variety of medical settings to a variety of medical healthcare personnel (Johnson & Jacobson, 1998b). In response to these challenges, Johnson and Jacobson (1998b) thus suggest that one way to achieve clinical identity is to educate the public about available services through maintaining high visibility. In a similar vein, for speech-language pathologists who share an interest in the treatment of MND, it is perhaps time that these therapists also came together in order to advocate for their patients and educate the public and HCPs involved in this disease about the value of the profession. Furthermore by engaging in patient and family support groups within the community (Johnson & Jacobson, 1998b), and forming alliances with the MND Association of South Africa for example, speech-language pathologists are given a further opportunity to market their services and achieve greater recognition and credibility, and thus establish a more defined clinical identity in terms of the management of MND.

A further means of achieving greater clinical identity is for the profession to develop clinical protocols (Pietranton, 1998). Although the aim of this discussion is not to provide an exhaustive list of ways to improve clinical visibility, the development of clinical protocols is nonetheless important because such tools have the capacity to strengthen a profession's identity and enhance the quality of care rendered (Pietranton, 1998). Apart from clinical protocols defining a specific set of procedures for an area of clinical practice, and stipulating the knowledge and skills that are required to perform such procedures competently, they also represent an explicit commitment on the part of the profession to maintain certain clinical standards and achieve certain ideals (Pietranton, 1998). In the case of the present study, the development of clinical protocols by speech-language pathologists who work in the area of MND may thus aid in convincing team members of the dedication and

commitment that the profession has towards the management of this clinical population. Furthermore by making such an explicit commitment, MND team members may feel more confident in referring their patients for speech-language pathology intervention, knowing that the profession has a specifically defined role and sense of devotion towards the management of this disease. Also such efforts may ensure that persons with MND consult only those professionals knowledgeable and experienced in the field, such that more positive speech-language pathology experiences may be yielded.

Perhaps a further rationale for the development of clinical protocols lies in the fact that such documentation has implications regarding the team approach that is proposed for the management of MND. Pietranton (1998) ascertains that in those environments where speech-language pathologists function as part of a team, discipline-specific clinical protocols are a necessity because they form part of a complete clinical pathway. Clinical pathways are multidisciplinary frameworks used to coordinate and streamline service delivery. By combining each discipline-specific clinical protocol, a clinical pathway is established that functions as a clinical management tool to guide the organisation, sequencing, and timing of major interventions provided by each healthcare profession (Pietranton, 1998). As a result clinical pathways therefore provide a preferred pattern of service delivery (Pietranton, 1998) such that, *“All the providers involved are on the ‘same sheet of music’ in terms of the what, when, and how of delivering care, but always have the option - and the responsibility - of altering the plan when the patient or circumstances warrant”*. (Pietranton, 1998:679). Notwithstanding the development of clinical protocols as a means for promoting and securing the clinical identity of speech-language pathologists who work in the area of MND, advantages also clearly exist in terms of contributing to the team approach and its logistics, and hence the overall management of this disease.

In relation to achieving a clinical identity and establishing a position in the referral network so as to enhance service delivery, good inter-professional collaboration and communication is essential (Reeves, Freeth, Glen, Leiba, Berridge & Herzberg, 2006). In other words if HCPs understand the role of speech-language pathologists in the management of MND, then referrals may improve given that collaborative

knowledge between professions contributes to an improvement in patient care (Reeves, 2001 as cited in Reeves et al., 2006; Reeves et al., 2006). Thus in addition to education efforts and the development of clinical protocols to inform other HCPs about the role and value of speech-language pathologists in the MND team, publications in various journals and books by these professionals may also allow for information about the profession to be disseminated. However while publications in speech-language pathology journals might encourage more speech-language pathologists to engage in this area of practice, it is questionable whether other team members would seek out this information of their own accord. On this basis it is perhaps time that MND researchers and clinicians in the discipline of speech-language pathology, broaden their publication base to address other members of the MND team. For example following perusal of the literature in various neurology journals, it was established that the treatment of MND or ALS is discussed most frequently in the context of different drug therapies. While this finding is understandable because the majority of consumers of this literature are likely to be those professionals who will prescribe such drugs, Sufit (1997) suggests that many physicians have lost sight of the fact that disease-specific intervention is only one aspect of the overall management of MND. Physicians are reportedly so focused on the etiologic aspects of a disorder in order to establish a definitive diagnosis, that they fail to focus their attention on identifying interventions that will lessen disease progression or provide symptomatic relief (Sufit, 1997). In two separate articles written by Leigh et al. (2003) and Sufit (1997) for example, the communication and swallowing impairment inherent to MND is discussed, along with various other complications that arise during the disease process. Although information is provided about the speech characteristics and the different types of alternate and augmentative communication systems available, as well as the swallowing difficulties and options for enteral feeding, minimal reference is made to the speech-language pathologist or the need for speech-language pathology services. For example practical information regarding the timing of referral for speech-language pathology intervention is not discussed, and nor is the role of this profession in the management of dysphagia highlighted. Also no mention is made of the collaboration that is necessary between HCPs and speech-language pathologists in order to provide the highest standard of service for this healthcare consumer base. Given however that the authors of these articles are not speech-language pathologists, it is recognised that one cannot expect

them to publish speech-language-pathology-specific material. Hence the need is clear for the discipline of speech-language pathology to extend the boundaries within which it publishes, so as to reach all members of the MND team and ensure that not only are they able to learn more practical and meaningful information about the profession, but also acquire inter-professional knowledge that is necessary to facilitate the management of persons with MND from a more holistic perspective.

In suggesting that speech-language pathologists publish more broadly to advertise their services, a responsibility does however rest with the profession to demonstrate that that which is advertised (i.e. treatment for persons with MND) is efficacious and effective. The fact that few participants of this study were referred for speech-language pathology intervention, and some participants perceived dissatisfaction in the services that they received, perhaps suggests that the profession has not proved its value in terms of the management of MND. Some HCPs may have therefore been reluctant to refer their patients with MND for speech-language pathology intervention given that in the absence of credible treatments, physicians see little purpose in making referrals for questionable interventions (Gelinas, 1999a). Tompkins and Lustig (2001) thus suggest that one of the most significant ways in which speech-language pathologists can gather credibility for their services rendered, is to accumulate sound evidence that justifies the efficacy and outcomes of speech-language pathology intervention. Moreover in an era where cost-benefit analysis of intervention is necessary and sometimes even enforced by healthcare funders, there is an urgency to generate solid evidence and justify clinical treatments in order to meet the requirements of best practice and demonstrate accountability to the public, reimbursing agencies, and HCPs (Kraemer, 2003; Tompkins & Lustig, 2001). Thus for speech-language pathologists who work in the area of MND, the time has possibly come to begin demonstrating the efficacy and effectiveness of interventions that are specific to the management of this disease. Such specificity is essential because although studies demonstrating the efficacy of speech-language pathology for a mixed spastic-flaccid dysarthria for example might prove that intervention is generally effective, one cannot be certain that such findings would hold true when a variety of variables inherent to MND are introduced to the system. Also while efficacy may exist for the use of a social approach in aphasia intervention, without disease-specific research there is no guarantee that the outcomes can be generalised to MND.

Moreover because healthcare consumers and healthcare providers expect objective information about the healthcare that is “purchased” or recommended (Frattali, 1998), it is not until a discipline has made an impact and demonstrated its worth that other HCPs will begin referring patients (Gelinas, 1999b).

Finally while it is evident that participants of this study perceived in general, negative experiences in terms of speech-language pathology intervention for persons with MND, steps can be taken to move the profession in a more positive direction. However in terms of the reliability of this study and the burdensome nature of MND, it is possible that at the time of data collection participants viewed their experiences through “tainted lenses”, resulting in an abundance of negative perceptions. While the nature of MND may be that it is in fact too difficult to perceive anything in a positive light in view of one’s impending death, asking participants to comment explicitly on positive experiences that had been encountered might have enhanced the value of this study. Positive factors that one could however infer, relate to the hope and value that some participants appeared to place on speech-language pathology intervention. For example the person with MND from Unit 2 stated that although she had never received speech-language pathology intervention, she believed that this form of treatment would have helped to reduce the tension and frustration that the communication impairment had created between herself and her friend. Furthermore the person from Unit 3 expressed her awareness regarding the fact that she needed to make changes to her communication, although she was uncertain of the appropriate modifications and therefore required assistance in this regard. For the two persons with MND who expressed their satisfaction with regard to the services that they had received, both individuals stated that speech-language pathology had been a beneficial form of intervention and more valuable than any other therapies that had been received. Although such comments may in fact be a socially desirable response given that the participants were aware of the researcher’s background, they may also be suggestive of the fact that when speech-language pathology intervention is implemented by an experienced and committed therapist, the possibility does exist for a positive impact to be made. Thus if speech-language pathologists can further their knowledge and skills in terms of the management of MND, and can prove the efficacy and effectiveness of their interventions, the likelihood exists that therapists and the profession alike will be able to secure a clinical identity and be acknowledged as a

credible member of the MND team. Furthermore if speech-language pathologists are viewed as influential in the management of MND, HCPs in the team may have more faith in referring patients for speech-language pathology intervention. Thus while greater proactivity on the part of speech-language pathologists may make the profession more visible and meaningful (Kagan, 1998b), one hopes that these steps towards making change will also enhance the overall value of the MND team for the ultimate benefit of healthcare consumers with this disease.

#### **4.1.2.2 Medical and Rehabilitative Management**

In line with the fact that participants of this study expressed dissatisfaction with regard to the medical and rehabilitative management that had been received, two related issues were identified. In the first instance it was established in the majority of Units that once the consulting physician had made a definitive diagnosis, persons with MND were not afforded any follow-up appointments. Secondly over and above the lack of referrals for speech-language pathology intervention, additional treatments were not recommended and nor were referrals made for other therapies that constitute rehabilitation. Moreover many HCPs were perceived to display a negative attitude towards intervention, stating that nothing could be done to help persons with MND. Whilst these perceptions are nonetheless only representative of participants who participated in this study, they are however in stark contrast to the fact that during a symposium held in 1979, it was discussed then already that the traditional view of MND being an impossible disease to treat does not hold true (Mulder, 1980). Consequently one cannot help but wonder why a quarter of a century later, HCPs implicated in this study appear to have made little progress in terms of managing persons with MND.

According to the Standard of Care Consensus on Diagnosis and Management of ALS, the spectrum of care from diagnosis until death can be divided into various stages (Miller et al., 1997). The aim of the initial consultation is for the physician to listen to the patient's opinions about his/her health status and conduct a routine examination. The physician should also inquire about the patient's goals for the visit (e.g. establish whether the consultation is to obtain a second opinion), order all appropriate diagnostic tests, and arrange a follow-up appointment after review of test results. During the second consultation the test results should be explained to the patient, any

physical and/or emotional changes should be discussed, and education should occur about MND and the difficulties surrounding diagnosis and the variability in the course of the disease (Gelinas, 1997; Miller et al., 1997). More importantly the patient should be offered some form of treatment, albeit pharmacological or psychological intervention. Following the second consultation, interval evaluations should be scheduled every two to three months (Miller et al., 1997). The aim of these follow-up appointments is to monitor the patient's health, attend to any treatable disorders, and continue with education about MND. A portion of these sessions should also focus on referring the patient to appropriate members of the MND team for rehabilitation, as this type of intervention is fundamental to bolstering the patient's morale and providing him/her with the strength necessary for coping with a debilitating disease (Gelinas, 1997; Miller et al., 1997). Follow-up appointments are therefore an essential component of MND management because they offer patients an opportunity to receive both counselling and intervention, which in turn allows them to stop obsessing about the disease and rather redirect their energies to other aspects of their lives (Gelinas, 1997). In light of these international standards, it is thus clear that not only were participants of this study denied an opportunity for follow-up appointments and referrals, they were also denied rightful opportunities to receive a comprehensive continuum of care. Also a sense of collaboration and partnership between HCPs was seemingly absent, indicating a lack of teamwork as the fundamental core of MND management. Thus in comparison to the Standard of Care Consensus on Diagnosis and Management of ALS (Miller et al., 1997), healthcare consumers in this study appeared to be subject to substandard MND management, and it therefore comes as little surprise that participants perceived a major breakdown in the continuity of their care, and felt isolated because they had been unable to establish meaningful relationships with their HCPs.

Whilst respecting the perceptions of the participants of this study, and the fact that the majority reported a lack of follow-up appointments and referrals for rehabilitation, a member of the focus group did however express that it is difficult to accept that six different physicians would all provide their patients with substandard management in this regard. As a result, this individual suggested that perhaps certain types of information exist that patients do not hear or process adequately and thus fail to act upon. Whether this is the case or whether six different physicians were in fact

inadequate in terms of the management of their patients, this finding nonetheless supports the need for information to be repeated on a regular basis. The importance of follow-up appointments is therefore reiterated so as to ensure that patients will at some stage during the disease process, hear and assimilate important information necessary for participating in different interventions and making decisions about their future.

In contemplating the possibility that the physicians associated with this study did however engage in substandard practice, then one needs to consider explanations for this behaviour in light of the fact that literature supports follow-up appointments and rehabilitation as important components of MND management (Gelinas, 1997; Miller et al., 1997). In the context of this study a possible explanation may relate to a lack of team involvement, and the fact that for some of these physicians they perhaps have not witnessed the benefits of rehabilitation and team intervention. Consequently they may have believed that the onus rests solely on them to improve their patient's condition. However in acknowledging their inability to alter the pathology of the anterior horn cell (Mulder, 1980), these physicians may have felt completely helpless and therefore withdrew from the situation entirely. Thus in order to protect their own well-being, physicians may have decided that it is simply easier to refrain from seeing patients with MND after making a diagnosis, and hence by telling these individuals that nothing can be done for them, follow-up appointments do not apply. Similar to experiences reported in the oncology literature where professionals experience extreme hopelessness anticipating a patient's death (Baider & Wein, 2001), some MND practitioners may believe that their inability to cure the disease is a sign of personal failure, and besides making a diagnosis for which they are capable, they should withhold any further contact with patients who have MND. Opposed to this belief however, Silani (1999) reports that most persons with MND are well aware that there is no cure for the disease, and simply want to be supported and informed about resources that are available to promote their quality of life. Physicians therefore need to realise that treatment is not the same as cure, and until such time that a definite cure is detected referral is essential, because apart from various drug therapies rehabilitation remains the best hope for improving the health, quality of life, and survival of persons with MND (Francis et al., 1999).



In light of the paternalistic attitude of some physicians who believe that it is their responsibility to cure because they occupy a position of power and authority (Ross & Deverell, 2004d), these HCPs possibly need to consider shifting their mindset away from a biomedical model of practice. If such professionals are able to realise that in the management of MND their role as educator, counsellor and advisor is far more important than lamenting over a cure, then they may feel more inclined to schedule follow-up appointments so as to offer their patients the best quality of care possible. After all the most valuable message that any HCP can convey to his/her patient with MND is one of commitment and care (Gelinas, 1997). Moreover by acknowledging that they are not solely responsible for the management of persons with MND, and that rehabilitation may at least offer symptomatic relief as opposed to no intervention at all, physicians may feel more inclined to encourage teamwork and become more active within the referral network. However in entering into the referral network, all HCPs are cautioned from viewing referral as just another phase in the management of MND. As evidenced in this study, whether participants sought their own therapists or were referred by a professional, those persons who consulted inexperienced HCPs who were limited in terms of their knowledge of MND, perceived unpleasant and negative experiences. HCPs involved in the management of MND therefore have a responsibility to ensure that not only are they competent to work with this patient population, but also that they refer their patients to credible members of the team. As discussed for speech-language pathologists, all disciplines in the MND team should thus engage in efficacy and effectiveness studies so as to promote their credibility and aim for higher standards of MND management. Greater collaboration, referral and teamwork between HCPs, may therefore aid in achieving greater continuity and a more comprehensive approach to the medical and rehabilitative management of MND. Finally in order to gain greater patient satisfaction regarding management efforts, some HCPs possibly may need to rethink their attitude surrounding the misnomer that MND is an untreatable condition – as one of the most traumatic experiences for a patient is to come to the realisation that there is nothing that can be done for him/her (Baider & Wein, 2001).

#### **4.1.2.3 Implications for the Medical and Rehabilitative Management of MND**

According to Dengler (1999) the management of MND varies significantly between countries, depending on healthcare organisations and national referral systems. In

accordance with the present findings however, it is questionable as to whether the behaviours of HCPs implicated in this study were based on any formal guidelines available for directing the management of MND. Whilst the current research cannot necessarily be generalised to all MND practitioners in South Africa, consequences such as isolation and lack of support are nonetheless inevitable when patients with MND do not receive appropriate intervention. Since a patient and his/her family must feel supported during the difficult period of coming to terms with a diagnosis of MND, Leigh et al. (2003) recommend that a comprehensive team management plan be devised as soon as possible after the diagnosis. However because South Africa does not appear to have its own policies in terms of acceptable management for MND, it begs the question as to what comprehensive MND team management is in this country. Local HCPs are therefore urged to draw on international standards of care in order to facilitate the development of comprehensive management protocols. Although recognising that international trends are not always compatible with the South African healthcare climate, for the time being they may offer HCPs the guidance necessary for drafting a national policy and hence improving the quality of management for persons with MND.

Whilst it appears that globally a multidisciplinary approach is recognised as the ideal standard of care for MND management (Francis et al., 1999; Leigh et al., 2003), in the case of South Africa it may be that the characteristics of this model are not compatible with the healthcare demands of this country. Rather a transdisciplinary model of intervention may better meet the needs of South Africa's current healthcare setting, given the country's imbalance between human needs and available resources (Ross & Deverell, 2004c). Because a transdisciplinary approach to intervention incorporates the knowledge and skills of many disciplines into one multi-skilled practice, intervention is received from primary providers and the number of individual professionals is reduced or their degree of involvement in various cases is limited. The essence of this approach is therefore based on role-release, whereby professional boundaries are eliminated so that the transference of specific skills, strategies, techniques and knowledge can occur across various disciplines in order to attain integrated yet cost-effective management (Golper, 2001). Moreover unlike a multidisciplinary approach, transdisciplinary models of intervention acknowledge the family as an integral component of the team and are therefore also described as

family-centred in nature (Golper, 2001; Shames et al., 1998). Consequently a transdisciplinary model may thus be well suited to the management of MND in South Africa, given the importance of the family in the Unit and the fact that it is this type of team approach that is most advantageous when intervention requires interfacing a number of related professional disciplines (Golper, 2001).

In relation to a transdisciplinary model of intervention, a more comprehensive approach to management may further be achieved through the use of a case manager to coordinate the team. According to Leigh et al. (2003), a case manager or case coordinator offers a single point of contact through which patients' needs can be channelled. In the United Kingdom general practitioners play a key role in the management of MND, and are responsible for coordinating MND teams and management programmes (Leigh et al., 2003). Given South Africa's scarcity in manpower however (Ross & Deverell, 2004c), and the fact that the role of case manager may place an additional burden on the HCP (Leigh et al., 2003), members of the focus group agreed that the coordination of management programmes need not necessarily be conducted by general practitioners. Rather any HCP can assume the role of case manager, provided inter-professional collaboration exists such that practitioners furnish this individual (i.e. the case manager) with lucid information about the intervention they provide, so that he/she can make sound management decisions (Tonkovich, 1998). Furthermore the value of a case manager in South Africa particularly, also lies in the fact that he/she plays an important role in attempting to control the costs of service delivery by negotiating between healthcare providers and healthcare funders (Tonkovich, 1998). To this end in collaboration with HCPs, the case manager may for example conduct a general assessment of need during interval evaluations with each patient, so as to ensure the delivery of all necessary healthcare services while at the same time avoiding unnecessary ongoing treatments. Thus regardless of which HCP adopts the role of MND case manager, he/she plays an important part in not only shaping and refining each patient's management programme and ensuring that the necessary therapies are received, but also in achieving more effective utilisation of the country's resources and more satisfactory perceptions with regard to the management of MND.

While transdisciplinary models of teamwork and the appointment of case managers evidently have the potential to improve the management of MND, such recommendations must be considered in relation to the financial burden of healthcare service delivery. Given the nature of chronic progressive disorders and the fact that a variety of treatments need to be sustained over a long period of time (Rotstein et al., 2006), conditions such as MND are considered “expensive diseases”. For example in the case of Unit 2, the person with MND explained that once she was unable to continue paid employment, her Medical Aid benefits ceased and she was no longer able to afford any healthcare services. Also her reduced mobility meant that the only way she could be transported was by ambulance, and the cost of this service alone translated into her being denied the opportunity to gain access to different types of intervention. Consequently a significant financial and emotional burden is placed on the affected individual and his/her family, as well as society at large (Rotstein et al., 2006). Moreover as discussed by a member of the focus group, attempts to alleviate this burden are likely to be hampered by the fact that there is no incentive to make a full-time business out of managing persons with MND. As a cure does not exist for the disease, there is no business imperative for multi-national pharmaceutical companies to invest in MND and consequently establish much needed MND clinics and/or comprehensive treatment programmes. Similar to the running of any other business therefore, one possibly needs to market MND to the public in the hope that somebody will “adopt” the disease and become the custodian of care, thereby also “adopting” the financial demands of the illness. However whilst this suggestion may provide a long-term solution for the financial challenges of MND management, in the interim period healthcare providers have a responsibility to provide the best possible quality of care to all healthcare consumers under the given circumstances (Pietranton, 1998). A challenge therefore rests with all HCPs involved in the management of MND, to develop innovative ways of securing resources from funding agencies in an attempt to achieve quality healthcare for this financially burdensome disease.

Finally with respect to the perceived dissatisfaction that participants reported in terms of the medical and rehabilitative management of MND, it is evident that there are plausible explanations underlying these findings. However given the international advances that have been made in MND management over the last 25 years, South Africa perhaps needs to follow suit to ensure that its healthcare consumers experience

more satisfactory healthcare encounters. Specifically, if speech-language pathologists aim to establish a definite clinical identity within the management of MND, this profession may achieve more acceptable healthcare experiences. Through the introduction of a team approach that is suitable to South Africa's healthcare needs, inter-professional collaboration and knowledge may also stimulate HCPs to engage in follow-up appointments and secure a healthy referral network in pursuit of comprehensive and continuous MND management. Furthermore given the challenges that have confronted and still do confront healthcare service delivery in South Africa, a team approach may be advantageous in relieving the burden of healthcare from one or two professionals, and collaboratively creating innovative means to secure resources. Also given that for the time being international guidelines may be one of the best ways to establish more acceptable MND management in South Africa, inter-professional knowledge and collaboration will serve MND practitioners well in modifying global standards in order to devise context-specific policies, protocols, and clinical pathways that will demonstrate cost effectiveness against a more comprehensive and coordinated approach to MND intervention efforts.

#### **4.1.3 Support Systems**

Literature pertaining to terminal illnesses particularly cancer, indicates that patients want to be viewed as individuals and treated with dignity and respect (Farrell & Lewis, 2000 as cited in Richardson, 2004). They want to receive the best treatments available, exercise control over their healthcare, die in a place of their choice, and engage with honest and sensitive HCPs. Patients also want to be assured that their family will receive the assistance and care necessary to cope throughout the disease period, even during the time of bereavement (Farrell & Lewis, 2000 as cited in Richardson, 2004; Richardson, 2004). On this basis patients and families require systems of support which include variables such as information, social care, psychological assistance, spiritual guidance, and direction to complementary therapies, and which function to help healthcare consumers live as best a life as possible under the given circumstances (Richardson, 2004). Furthermore in accordance with the recommended patient-centred approach to care, professionals are expected to not only meet the biomedical needs of their patients, but also broaden their perspective and provide social, emotional and psychological support (Mead & Bower, 2000). In view of the ideals of support and patient-centred care however, the

results of the present study were to the contrary in that most participants perceived medical professionals to be unsupportive and lacking compassion during the disease process. Participants indicated that because HCPs gave the impression that MND is a death sentence, they seemed to demonstrate little concern or care towards their patients and offered no hope or encouragement for the future. Furthermore although HCPs were perceived to provide greater warmth and compassion to family members than to persons with MND, several of these family members still felt that they were unsupported throughout the course of disease progression. In addition, despite support groups offering an invaluable source of strength for coping with MND (Gelinas, 1997), participants of this study yielded mixed perceptions in terms of the value of available support networks and resources. Such results therefore support the literature in that it is imperative for HCPs involved in the management of MND to focus on team intervention and patient-specific approaches, as well as identify support systems and resources available to both persons with MND and their family members (Gelinas, 1997; Richardson, 2004). After all healthcare consumers look towards their HCPs to meet their needs and subsequently reduce any disruptions to their quality of life (Rose, 1990 as cited in Arora, 2003).

#### **4.1.3.1 Providing Supportive Care**

In line with the findings of the present study, many occurrences of a lack of support were demonstrated in one way or another. For example several participants reported feelings of isolation and loneliness, not because they were alone socially but because they felt that they had been abandoned by their HCPs in terms of the continuity of their care. Also because appointments were rushed and in some cases the communication impairment compromised the pace of the consultation further, several persons with MND stated that they were unable to discuss their concerns with their HCPs and therefore felt afraid about the future. However, possibly two of the most important illustrations of a lack of support relate to two of the five key dimensions that comprise Mead and Bower's (2000) definition of patient-centred care. Firstly in terms of "patient-as-a-person", the majority of individuals with MND perceived themselves as inferior in the healthcare consumer-professional relationship. Such relationships were reportedly characterised by inequality, whereby HCPs treated family members with more support and respect than they did persons with MND. Several persons with MND therefore felt that their HCPs had failed to regard them as

competent and independent human beings in their own right. This report raises subsequent concern in that Rutherford and Foxley (1991) state that when a person is diagnosed with a terminal illness, changes in his/her self-concept are bound to occur such that significant emotional and psychological distress is created. HCPs therefore need to acknowledge their patients as worthy and fully-fledged human beings, so as to not only reassure them about the normalcy and legitimacy of their reactions and concerns, but also to compensate for threats posed to their self-image (Arora, 2003; Rose, 1990 as cited in Arora, 2003). With respect to the second dimension of “therapeutic alliance”, participants reported a lack of compassion and unconditional positive regard on the part of medical HCPs. The core attributes of empathy and congruence that enhance the relationship between patient and HCP (Mead & Bower, 2000) were therefore absent in the present study. Similarly such lack of support and patient-centred care is also evident in the literature, where Jotkowitz and Clarfield (2005) state that in general many patients and even HCPs often comment on the limited empathy, compassion, and regard for psychosocial factors that is portrayed by healthcare providers. However given that the participants of this study reported a desire to be treated as individuals and by sensitive and compassionate HCPs, rather than accepting Jotkowitz and Clarfield’s (2005) findings as the norm, researchers and clinicians possibly need to invest time and effort in developing comprehensive treatment programmes that foster support and sustain a culture of compassion.

Further to the lack of support demonstrated in this study, a study conducted by McDonald, Wiedenfeld, Hillel, Carpenter and Walter (1994), revealed that the psychological well-being of patients with ALS increases survival time independent of age, length of time since diagnosis, or disease severity. For this reason alone, providing patients with the necessary support and care is a fundamental component of any MND management protocol (Francis et al., 1999). However despite researchers and clinicians acknowledging the importance of supporting patients and attending to their psychosocial needs (Francis et al., 1999; Gelinas, 1997; Leigh et al., 2003), this only seems to be mentioned in passing in the literature and does not appear as an integrated component of mainstream MND management. In order that MND healthcare might become more integrative and holistic by meeting both the biomedical and psychosocial needs of healthcare consumers, MND practitioners may perhaps derive benefit from drawing on the advances that have been made and the

treatment frameworks that have been adopted in terms of the management of cancer. According to Ahmedzai et al. (2004), as a result of the fact that most patients with cancer will ultimately die from the disease, the side-effects, or complications arising from treatment, a new model of care has been implemented by healthcare providers that places more emphasis on the psychosocial aspects of intervention than on the curative aspects of intervention. Psychosocial support is thus delivered in the form of supportive care, which is a new treatment framework whereby patient and family care needs are met at every stage of the cancer journey by any member of the oncology team (Ahmedzai et al., 2004; Fincham, Copp, Caldwell, Jones & Tookman, 2005; Richardson, 2004). Because this approach places the patient and family at the centre of their treatment regime, they are empowered to make informed decisions and play an active role in their own management (Ahmedzai et al., 2004; Fincham et al., 2005; Schapira, 2003). In essence supportive care therefore aims to achieve the optimal well-being of patients and families from the time of diagnosis to bereavement, and also emphasises assisting individuals to find meaning in their lives by focusing on living while simultaneously acknowledging and preparing for death (Ahmedzai et al., 2004; Fincham et al., 2005; Richardson, 2004).

In view of the tenets of supportive care and the fact that the use of this approach across Europe has resulted in highly effective services being delivered to persons with cancer (Richardson, 2004), its application to the management of MND could perhaps yield similar benefits. Since the reality of MND is that the emotional sequelae and death will remain inevitable unless a drug or clinical procedure can be discovered that will cure an individual of the disease, interim management options are worthy of consideration. Thus in relation to supportive care it seems apt to suggest that if persons with MND and their families are placed at the centre of their management plan and given the opportunity to exercise genuine choice about their treatment and care, then they may be placed in a position to create a life for themselves that they perceive as acceptable according to their own standards. Self-management is after all an important component of supportive care because as Richardson (2004) states, often the only way to deal with a problem for which there is no solution is to allow the patient to deal with it in his/her own manner. In this sense supportive care is therefore about HCPs being facilitators of self-management, and becoming attune to the needs of their patients in order to guide and equip them with the tools necessary to direct



their own lives (Richardson, 2004). Similarly as suggested in the previous theme, possibly one of the most important roles that HCPs can assume in the management of MND, is to educate, counsel and advise patients and families in terms of directing their own lives. By applying the principles used in the care of patients with cancer, and replicating similar investigations in the area of MND, it is therefore anticipated that supportive care has the potential to also improve the quality of care and support, and thus the quality of life for persons with MND and their families.

#### **4.1.3.2 Support for Family Members, Significant Other Persons and Caregivers**

In most terminal illnesses more than half of the care that a patient requires will be carried out at home by a family member, significant other person, or formally trained carer (Jansma, Schure & Meyboom de Jong, 2005). While the role of carer poses significant challenges in almost every terminal disease, it is said that in the case of MND the physical and psychological burden placed on family members and/or caregivers is even more overwhelming (Jansma et al., 2005; Krivickas et al., 1997). Compared to the care required for Alzheimer's disease, Multiple Sclerosis, and post-stroke patients for example, greater physical and emotional demands arise for the family member or caregiver of a person with MND, given the disease's more rapid progression and severely disabling final stages (Krivickas et al., 1997). Consequently in line with these literary reports and the fact that most family members in this study perceived dissatisfaction in terms of the support that they had received as caregivers, it is imperative that families and carers involved in the management of MND be offered the necessary supportive structures in order to reduce the caregiver burden as much as possible.

Apart from the burden placed on a family member or caregiver when caring for a person with MND, when this individual provides care within the family and shares a specific physical and/or psychological space, he/she forms part of an interconnected system that is comprised of interdependent components (Goldenberg & Goldenberg, 2000 as cited in Ross & Deverell, 2004b; Ruble, 1999 as cited in Ross & Deverell, 2004b). Furthermore because the family is a system that functions as a single unit or team, when caring for an individual with a terminal illness one cannot separate the patient's needs from those of the family member or caregiver (Fisher, 1991; Trail et al., 2003). Family systems theory therefore dictates that when providing support for a

patient, it is better to work at the level of the family and adopt a family-centred approach to intervention, so that any improvements that occur will encompass all members of the system (Ross & Deverell, 2004b). As a result in addition to providing a continuum of support and care for persons with MND, the meeting of family members and caregivers' needs should also become an integrated part of mainstream MND management. Hence the application of supportive care is further highlighted as a viable treatment framework in the management of MND, because this approach assists both the patient and the family in coping with the terminal illness (Richardson, 2004). However one should note that although this study did include family members' perceptions about the management of MND, greater emphasis was placed on the management and support that was provided to persons with MND. Little attention was given to family members' needs or how they were supported during the disease process. The value of future research may therefore lie in studies that investigate management, support and intervention at the level of family members and caregivers, as Leigh et al. (2003) believe that the support required by these individuals should be viewed with equal importance to that of the care and support required by persons with MND.

Notwithstanding the perceptions of family members reportedly being treated by HCPs with greater warmth and compassion than persons with MND, these individuals nonetheless felt unsupported and ill-prepared to adopt a caregiving role. Specifically concerns arose in terms of practical issues such as transferring the person with MND, assisting during feeding, and understanding the individual's daily needs in the presence of a communication impairment. On numerous occasions throughout this study participants therefore raised the need for caregiver training. In line with the fact that Jansma et al. (2005) state that family members and caregivers involved in palliative care rate practical information as one of their most important needs, implications arise for all members of the MND team to assist families or caregivers in adopting and sustaining a caregiving role. For example in response to the findings of this study, speech-language pathologists would play an important role in providing family members and caregivers with techniques for engaging in effective communication, so as to reduce the tension that the communication impairment might cause within the Unit. Also family members and caregivers could be trained to assist the person with MND in achieving safe feeding. In bearing these recommendations in

mind however, Jansma et al. (2005) indicate that family members who adopt a caregiving role usually face two major challenges. Not only are they required to engage in tasks that demand practical skills unfamiliar to them, but they are also confronted by psychological problems relating to the care of a loved one. While it is true that family members can be trained to acquire the practical skills necessary for meeting the physical demands of the person with MND, they are likely however to lack the professional distance that is required when providing care on a daily basis. As a result certain requirements of the caregiving role may create the potential for family members to experience significant levels of stress and/or depression, as well as for friction to arise within the family system (Jansma et al., 2005). Furthermore studies pertaining to Alzheimer's disease and Multiple Sclerosis have shown that not only does the burden of caregiving increase the incidence of depression and deficits in physical, mental, and social health when compared to age-matched non-caregiving controls (Kalb, 1995 as cited in Krivickas et al., 1997; Olin, Schneider & Kaser-Boyd, 1996 as cited in Krivickas et al., 1997), but also patients are placed at risk for receiving sub-optimal home care (Evans, Bishop & Haselkorn, 1991 as cited in Krivickas et al., 1997). Consequently in an attempt to restore a carer's personal well-being and achieve equilibrium within the family system, there is a clear need for MND team members to provide family members and caregivers with emotional and psychological support beyond skills training and assistance with the practicalities of caregiving.

In relation to fulfilling a caregiving role, as MND progresses and the affected individual begins to experience a greater degree of disability, a point in time usually comes when the family member or carer is unable to cope alone. At this stage outside assistance brought to the home is required, or institutionalisation may also be considered (Krivickas et al., 1997). Reportedly however almost all persons with MND prefer to remain in their homes as their condition deteriorates (Krivickas et al., 1997), as confirmed by all participants with MND in this study who stated that they wanted to die at home. When persons with MND choose to remain at home, literature suggests that community-based intervention such as home healthcare should be implemented to maximise the individual's function and quality of life. Typically home healthcare includes services rendered to the patient at his/her home by HCPs such as nurses, hospice workers, physiotherapists, occupational therapists, and

speech-language pathologists (Krivickas et al., 1997). In accordance with the findings of the present study however, although persons with MND were living at home and being cared for by family members and/or caregivers, no home healthcare services were received apart from irregular visits by a representative of the MND Association of South Africa. If these persons with MND did require healthcare assistance they had to travel to the HCP themselves, despite this being made more and more difficult in view of their increasing lack of mobility. Furthermore, in South Africa the status of home healthcare service delivery is also questionable. A lack of resources and fragmentation in the healthcare system, coupled with the country's health policy that focuses on primary health and addressing the most common health problems in the community (Ross & Deverell, 2004c), means that the delivery of community-based healthcare to persons with MND is unlikely to take priority. The soaring number of individuals infected by HIV/AIDS in South Africa, along with the enormous stress that this places on the country's healthcare system (Ross & Deverell, 2004e), suggests that in the presence of home healthcare services, attention is more likely to be placed on this clinical population than on MND. Moreover with regard to institutionalisation, the family member from Unit 2 stated that when she investigated this option, many institutions and organisations refused to admit the person with MND because care personnel reportedly have limited knowledge of the disease. By virtue of a lack of resources and funding issues, as well as the low-ranking popularity of this disease, it is thus clear that many persons with MND are likely to live-out their time at home whether this is their intention or not. Family members' perceptions of the need for greater practical information and emotional support must therefore be considered of grave importance, so that families and caregivers can be equipped with the knowledge and skills required to care for persons with MND for the entire duration of the disease.

Finally because it is unlikely that in relation to resource distribution MND would be perceived as a high priority disease, the introduction of home healthcare may be one of the best possible ways of providing comprehensive healthcare to all South African persons with MND and their families. In overcoming some of the issues of mobility by taking healthcare services to patients, community-based interventions are beneficial because larger numbers of patients can be reached at less cost (Ross & Deverell, 2004c). Also in relation to the recommended transdisciplinary model of

intervention for MND management in this context, community-based work is particularly relevant in South Africa where fewer professionals are expected to do more work (Ross & Deverell, 2004c). While the potential benefits that community-based interventions might have for the management of MND in South Africa are therefore evident, issues of bureaucracy such as funding, cost-benefit analyses and the incidence of MND, are nonetheless likely to impose significant challenges for healthcare providers. As discussed throughout most of this chapter, a responsibility therefore lies with HCPs to advocate and be the voice for persons with MND and their family members or caregivers. By demonstrating to healthcare funders and stakeholders the benefits and costs of taking healthcare services to healthcare consumers, HCPs may be able to secure more accessible healthcare services for all individuals affected by MND. In the interim however, while healthcare providers work towards attaining high standards of equally accessible MND management, modifications to international recommendations such as the introduction of a transdisciplinary model of care and the use of key practitioners to provide a variety of services, lay the foundation for persons with MND and their family members or caregivers to begin gaining access to the services and support that they require whilst living in a resource-restricted society.

#### **4.1.3.3 Support Networks**

According to Krivickas et al. (1997), a further means of reducing the burden of terminal care for family members and caregivers is to increase the involvement of formal support networks, including support groups and support associations or agencies. For persons with MND and their families, support networks are said to play a fundamental role in the overall management of the disease (Leigh et al., 2003). These support systems not only provide opportunities for individuals to learn more about MND through books and pamphlets, but also patients and their families derive considerable informational and emotional care from interactions with HCPs who are knowledgeable in the field. In addition considerable emotional support can also be derived from persons with MND and their families engaging with other individuals who themselves contend with MND on a daily basis (Kasarskis, Elza, Bishop & Spears, 1997; Leigh et al., 2003).

With respect to the mixed perceptions that were elicited in terms of support networks, the majority of participants were generally satisfied with the information that these organisations provided about MND, and the fact that in some cases assistive devices (e.g. walking aids and wheelchairs) were loaned to persons in need. On the other hand however many participants felt that beyond information, a comprehensive approach to care and support was severely lacking. For example dissatisfaction was reported in terms of the inconsistency and infrequency of visits from representatives of support associations, as well as their inability to locate professionals in the participant's area and/or suggest the need for rehabilitation. Also the fact that some HCPs were unaware of available support networks was deemed problematic, along with the constant emphasis that certain representatives placed on death. At first glance these findings may therefore suggest that MND support networks are fragmented and poorly run. However by looking at these results beyond a superficial level, one may begin to better understand how MND support networks operate, and such explanations may in turn reveal areas where change can be implemented.

Possibly one of the main reasons why support networks appear to be failing MND healthcare consumers, is because of a lack of communication between HCPs and representatives of such support networks. For example the fact that some HCPs were unaware of available support associations for persons with MND, possibly highlights the need for these organisations to place greater emphasis on advertising their services. Likewise because support network representatives were unable to assist persons with MND in locating appropriate rehabilitation services, HCPs who are knowledgeable and skilled in the area of MND practice possibly need to ensure that their expertise are made known to the appropriate organisations. After all given that it was demonstrated in this study that healthcare consumers reported negative healthcare experiences when consulting HCPs who lacked experience and knowledge of the disease, it is essential that patients be referred to well-informed and credible professionals. In view of these findings a clear need therefore arises for communication and collaboration to occur between HCPs and support network representatives, so as to ensure that all healthcare providers are aware of the full array of services that constitute a comprehensive approach to the management of MND. Furthermore such collaboration between all HCPs and support network representatives serves as a reminder of the importance of a team approach for the

management of MND, and the fact that the success of the team and thus the management of the disease, depends on excellent channels of communication between all individuals involved in caring for the patient and his/her family and/or caregivers (Leigh et al., 2003). Finally in taking communication and collaboration between all MND healthcare providers to new heights, HCPs may look towards extending available support networks by establishing a healthcare database. Within this database all persons with MND and all healthcare providers committed to the management of MND could be listed, such that a type of directory is created and distributed to all MND practitioners, support network representatives, and healthcare consumers. Furthermore given the role of the Internet in healthcare (McMullan, 2006) and the use of this technology by MND healthcare consumers, a healthcare directory could be made available online for quick reference by practitioners, and could function as a means of support should patients consult HCPs who fail to furnish them with information about treatment and referral.

As demonstrated throughout most of this study, funding issues appear to have had a considerable influence on the management of MND. It therefore seems unlikely that the functioning of support networks would have escaped this reality, and the dissatisfaction perceived by some participants regarding these organisations may in part be a consequence of such financial constraints. As suggested during the focus group discussion, because various South African support organisations do not receive financial backing from large stakeholders, they need to secure their own stability in terms of finance. Hence for MND support networks it is likely that they also operate on limited resources and manpower, and staff members may work on a volunteer basis or for minimal remuneration. As a result it is perhaps understandable why participants in this study perceived service provision to be inconsistent and infrequent. Moreover because staff members are confronted by MND on a regular basis, the prospect of death and dying is a frequent reality for them. In response to this chronic emotional strain of working with such a clinical population regularly, certain support network representatives may subsequently begin to feel overwhelmed by the emotional demands imposed by persons with MND and/or their families. This emotional exhaustion may in turn lead to an experience of depersonalisation or an attitude of indifference regarding the needs of persons with MND and their families, as well as a sense of inadequacy and reduced personal accomplishment. In the

presence of this emotional state a person is said to be suffering from burnout, where there is a misfit between the demands of the environment and the individual's coping resources (Maslach, 1986 as cited in Ross & Deverell, 2004f; Ross, 1997 as cited in Ross & Deverell, 2004f).

Within the healthcare arena burnout of professionals reportedly has the potential to lead to inferior service delivery, and patients may even be treated in an uncaring manner (Ross & Deverell, 2004f). Although it cannot be said that the support network representatives implicated in this study were suffering from burnout, it is possible that the nature of their work does place them at risk for this type of stress. Experiences such as depersonalisation and a general negative attitude may in part have contributed to the portrayal of an impression whereby some participants perceived support network representatives as focusing too heavily on death. As a result of the complexity of factors that have the potential to give rise to burnout in support network representatives, such persons in addition to those with MND and their family members, require supportive care in an integrated MND management programme. Notwithstanding the management of burnout being beyond the scope of this discussion, the importance of team intervention might be revisited in the future and extended with respect to its capacity for controlling HCP stress. As Baider and Wein (2001) explain, it is through sharing burdensome experiences with diverse disciplines that HCPs are offered an opportunity to gain a new perspective on the burden of work and responsibility. Moreover this cost effective means of debriefing and providing colleague support is important because it is only once HCPs are provided with the support and care necessary for coping with the uncertainty and ambiguity of death (Baider & Wein, 2001; Ross & Deverell, 2004f), that they can offer the support and care that patients and families need to enhance their own well-being and find meaning in their lives.

In conclusion, given the multifaceted nature of MND and the fact that healthcare consumers present with both biomedical and psychosocial needs (Leigh et al., 2003), an integrative approach to management that acknowledges explicitly individuals' emotional and psychological sequelae may be most suited to this patient population. By adopting a new treatment framework such as supportive care, the potential exists for HCPs to meet both the biomedical and psychosocial needs of patients, and



consequently practise from a more patient-centred approach to care. In addition because supportive care acknowledges the needs of family members and caregivers (Richardson, 2004), implications arise for these individuals to be provided with practical information as to how to engage in a caregiving role and thus fulfil the need of the person with MND to die at home. By implementing supportive care through a community-based intervention such as home healthcare, the possibility also exists for MND healthcare consumers to have access to healthcare services irrespective of their physical status. However although community-based interventions may offer persons with MND and their families the best chance of comprehensive healthcare, MND practitioners will need to advocate for these services. Furthermore in order to coordinate supportive care and community-based intervention, communication and collaboration between all MND practitioners and support network representatives is fundamental for success and a more supportive approach to MND management. Finally it is when these support systems are in-situ, that MND healthcare consumers may perceive MND management as a more dignified and respected process.

#### **4.1.4 Complementary and Alternative Medicine**

When some patients face the realisation that their declining health is unlikely to improve, and available medical treatments may be ineffective or unable to provide a cure, they are often willing to try any means possible that will offer them hope and the prospect of recovery. As a result these patients may begin to investigate alternative approaches to the traditional medical interventions that are initially sought (Deverell, Vorobiof & Ross, 2004; Newbury, 1991). Alternative medicine, otherwise known as complementary and alternative medicine, includes the use of various substances and methods that are contrary to the principles of traditional “orthodox” medicine or allopathic healthcare (Eskinazi, 1998). Generally the techniques that are utilised in alternative medicine are not considered as standard medical treatments, and would therefore not be taught at medical schools (Eisenberg et al., 1993 as cited in Wasner, Klier & Borasio, 2001). In accordance with the results of the present study, several participants stated that because the medical profession had been unable to provide them with long-term solutions, out of desperation for a cure or even partial recovery they were prepared to search for answers elsewhere. Many of these individuals therefore reported not only having consulted an alternative professional at some stage during the disease process, but also perceived satisfaction in terms of the

communication, support, care, and intervention that was received from such treatment. The trend in industrialised western healthcare to investigate alternative medicine is thus said to be attributed to a growing dissatisfaction or lack of confidence regarding allopathy (Ernst, 2002). As confirmed by Wasner et al. (2001), ALS is no exception to this trend given that many patients reportedly turn to complementary interventions in view of the lack of success that medical therapies have to offer. Moreover the popularity of complementary and alternative medicine seems to stem from the fact that not only are alternative treatments more congruent with an individual's personal values and beliefs, but also because patients are encouraged to engage in interactions with HCPs and play a more active and autonomous role in their own healthcare, they are offered a sense of hope for the future (Astin, 1998; Fulder, 1998; Kaptchuk & Eisenberg, 1998). In essence therefore, because the participants of this study perceived the need for improved health communication and more autonomous healthcare that is congruent with their personal belief system, healthcare consumer satisfaction and hope for improved MND management may possibly lie in the extension of MND treatment principles beyond an allopathic healthcare paradigm.

#### **4.1.4.1 Health Communication and Healthcare Consumer Satisfaction**

With regard to health communication, all participants who engaged in complementary and alternative treatments perceived satisfaction in terms of this area of healthcare. Although persons with MND and their families were not asked to compare alternative professionals to medical HCPs, participants nonetheless reported that alternative practitioners made less use of clinical jargon compared to their medical counterparts, provided clearer and more understandable explanations of MND, and even facilitated the communication of persons who were communicatively impaired. Alternative professionals were therefore perceived to be more skilled and more effective in their ability to interact with patients during healthcare encounters, including those interactions with patients who experienced communicative difficulties. Such findings raise the question as to why alternative professionals were perceived to be more adequate in terms of their communication abilities relative to medical HCPs. Furthermore the question also arises as to whether the perceptions of satisfactory health communication in this context were based on a theoretical perspective of communication, whereby mechanistic processes allow senders to encode and

receivers to decode messages (McLaughlin, 1998), or whether participants viewed communication more in terms of its social and affective capacity to influence the behaviour of other individuals (McLaughlin, 1998).

In response to the preceding questions, a search of the literature at the time of this study revealed a dearth of information regarding health communication in the domain of complementary and alternative medicine. Several explanations have thus been proposed by the researcher, which may provide a rationale for alternative professionals being perceived as good communicators. Firstly although acknowledging and respecting the right of participants to their own opinions and perceptions, it is possible that the responses of these individuals were somewhat exaggerated at the time of data collection. Given that persons with MND would have consulted a medical HCP at the outset of the disease, and would have received the life-altering diagnosis from this practitioner, participants may as a result have developed a negative and hostile attitude towards the medical profession. Consequently all subsequent medical healthcare experiences may have been tainted by these initial emotions and perceived as less than satisfactory, including the communicative interactions that transpired between participants and HCPs. On the other hand when consulting complementary and alternative professionals however, participants were likely to have done so in an attempt to find hope or some kind of a solution to the changes that were threatening their future. Believing that traditional medicine had perhaps failed them, and that their only chance for solace lay within an alternative healthcare paradigm, these individuals may have thus viewed alternative healthcare encounters and the associated communicative relationships in a more satisfactory and positive light.

A second reason when considering why participants perceived alternative professionals to be better communicators than medical HCPs, possibly relates to healthcare consumer satisfaction. Amongst other factors, good communication skills and longer consultation times have a positive impact on the satisfaction of healthcare consumers (Probst, Greenhouse & Selassie, 1997). However because models of managed care in traditional medicine have reduced the length of patient consultations, medical HCPs are often rushed during appointments and afforded less time for quality communicative transactions between themselves and their patients. Consequently the

potential to develop strong healthcare consumer-professional relationships is likely to be hindered, and this in turn may diminish patients' experiences of a supportive healthcare environment and reduce their overall satisfaction regarding the healthcare encounter (Shinto, Yadav, Morris, Lapidus, Senders & Bourdette, 2005). In contrasting this explanation however, because complementary and alternative medicine is still a growing profession and generally less common than allopathic healthcare, it is likely that alternative professionals are less busy than medical HCPs. Furthermore given that complementary and alternative medicine is "whole person oriented" and focuses on each individual's entire life circumstances (Shinto et al., 2005), time per visit with an alternative professional is perhaps increased relative to traditional medicine, thereby allowing these practitioners to spend more time attending to each patient holistically. As a result of longer consultations, alternative professionals are therefore likely to provide their patients with greater communicative opportunities, and in doing so also enhance the potential for improved healthcare consumer-professional relationships, and improved healthcare consumer satisfaction in general. Similarly as demonstrated by Shinto et al. (2005) in their study on the perceived benefit of complementary and alternative medicine in Multiple Sclerosis, alternative professionals were found to spend more time per visit with patients than neurologists or medical practitioners spent, thus fostering stronger and more supportive patient-alternative professional relationships. Importantly the issue of extra time is also likely to have been particularly advantageous in the case of MND. Longer consultation times would have meant that not only were persons with MND and their families offered reasonable opportunity to interact with practitioners and discuss their healthcare, but also in the presence of the communication impairment alternative professionals may have felt less rushed and more willing to listen to the patient and facilitate his/her communicative attempts. In return persons with MND may have therefore experienced a greater sense of equality in terms of the patient-professional communicative relationship, thereby resulting in more positive health communication perceptions and hence improved healthcare consumer satisfaction with regard to the overall alternative medicine healthcare encounter.

Finally better communication on the part of alternative professionals may have also revolved around a very practical issue, one of skill and experience in meeting the emotional and communicative needs of persons with MND and their families.

Reportedly, individuals with a variety of neurological conditions attend the stem cell treatment centre in Germany. HCPs at this centre are therefore likely to confront families on a daily basis who bear emotionally burdensome conditions, and who are desperate for some form of relief. In addition it is also likely that these professionals frequently come into contact with persons who are severely disabled and/or communicatively impaired. Understanding the emotional burden that challenges these families, and the difficulties that arise in healthcare encounters due to impaired communication, these professionals have perhaps acquired and mastered the communicative skills that not only meet the patient's and the family's care needs, but also the communicative requirements of a given situation. Consequently for the participants from Unit 4, their perceptions regarding the communication of HCPs in Germany may have been based on the fact that by virtue of experience, such practitioners knew how to provide care that was congruent with this Unit's values, beliefs and needs, and was therefore perceived as satisfactory even in the presence of the communication impairment. Likewise, the same explanation could also apply to certain medical HCPs. Because some participants stated that medical HCPs with knowledge and experience in MND were good communicators, their understanding of the disease and familiarity in terms of facilitating communicatively impaired individuals and meeting their emotional needs, may have contributed to the satisfactory perceptions of health communication and healthcare encounters that were reported in this study.

In accordance with the explanations in the preceding paragraph, when an emotionally burdensome condition is exacerbated by a communication impairment, it thus appears that patients perhaps do not necessarily desire good mechanistic communication. Rather than the correct number of linguistic units for example (Epstein, 2000), patients may tend towards the presence of a sensitive HCP who is knowledgeable of the health condition, skilled in modifying and making effective use of communication, and provides the individual with time to express his/her informational and emotional needs. Thus albeit that the results of this study demonstrated flaws in mechanistic communication which undoubtedly need to be addressed, it is possible that the use of affective communication may function as an effective means for fulfilling the communicative and emotional needs of persons with MND and their families. In other words an affiliation style of communication that is

characterised by a professional's warmth, friendliness, openness and attentiveness (Leopold et al., 1996), may have helped participants in alternative medical situations to feel at ease in expressing their thoughts and opinions, and engaging more actively in their own healthcare (Fossum & Arborelius, 2004). Furthermore since affective communication also appears to be compatible in meeting the requirements of patient-centred communication, implications again arise with regard to communication training and assisting HCPs to acquire the practical skills necessary for addressing the psychosocial issues of patients, and arriving at a deeper understanding of what it means to be a truly responsive communicative partner (Del Piccolo, Putnam, Mazzi & Zimmermann, 2004; Stewart et al., 2000). After all the goal of health communication is not for HCPs to achieve a requisite number of open-ended questions or empathic-sounding responses during a healthcare encounter, but rather to arrive at a deeper level of connection with the patient (Stewart et al., 2000). Thus while it might have appeared at the outset of this study that alternative professionals were better communicators than their medical counterparts, it is not so much about alternative versus medical practitioners, or about German versus South African practitioners as it is about skill, the environment, and the attitude of HCPs being conducive to a style of health communication that provides support, affiliation, sensitivity and care, and ultimately yields greater healthcare consumer satisfaction.

#### **4.1.4.2 Fostering Hope**

Further to the satisfactory experiences reported with regard to alternative medicine, and in particular the health communication associated with such practitioners, persons with MND stated that the various complementary interventions that they had pursued had also been beneficial in that they had made a positive difference to their lives in general. Even family members who were not direct recipients of these treatments indicated the value of alternative medicine. In considering these perceived benefits however, empirical studies that investigate the physiological or health effects of alternative medicine on persons with MND could not be sourced. It is thus assumed that the participants of this study perceived the benefits of these treatments to have arisen from a more psychosocial basis, given that anecdotal evidence supports the use of an alternative healthcare paradigm as a means for offering support and providing MND healthcare consumers with a positive sense of well-being (Leigh et al., 2003). Moreover in relation to these psychosocial advantages, one of the most salient

contributions of complementary and alternative medicine for neurologically impaired persons, is that of hope or the perceived benefits and expectations of such interventions for one's future (Astin, 1998; Ernst, 2002). Therefore in the fostering of hope for healthcare consumers, because some individuals believe that alternative treatments have the potential to make an improved difference to their existence, a state of mind ensues that impacts positively on their attitude towards life and functioning, and energises them to bear the disease with fortitude and seek plausible alternatives to the current situation (Kim, Kim, Schwartz-Barcott & Zucker, 2006; Roberts, Johnson & Keely, 1999).

According to Kim et al. (2006), a relationship is said to exist between hope and how persons cope with periods of uncertainty. When patients who are terminally ill realise that no medical cure exists to treat their disease, they are often left feeling anxious about the future. In order that they might cope Newbury (1991) suggests that hope must somehow be restored, and the individual must be reminded that his/her life is still worthwhile. By "seeking-out" and "testing" alternative interventions at this stage of the disease process, individuals are therefore able to instil in themselves a sense of hope or a source of strength to cope and move forward into the future, even if prospects for the future appear limited (Smith-Stoner & Frost, 1999 as cited in Kim et al., 2006). Given that the participants of this study indicated that they were willing to try any forms of intervention available, and persons from Unit 4 even reported the pursuit of illegal substances in order to acquire a solution, evidence exists to demonstrate these individuals' quest to find hope or a driving force to help them focus on the future, cope better under the given circumstances, and take control of their entire being and functioning (Kim et al., 2006; Roberts et al., 1999). After all participants confirmed this finding by stating emphatically that they wanted HCPs to offer them genuine hope and encouragement for the future, rather than a constant focus on negativity and on MND being a death sentence. Hope as Simpson (2004) expresses is more than just an attitude that can make a positive difference in a patient's healthcare experience, it is also a requirement necessary for survival in that if a patient's hopes are dashed, so too may his/her will to survive be destroyed (Hunt, 1991). Thus irrespective of the fact that future research may be indicated for the scientific investigation of complementary and alternative medicine in controlling symptoms and effecting physiological change in MND healthcare consumers, the

psychosocial and emotional benefits of this healthcare paradigm are nonetheless undeniable. By fostering hope and as a consequence providing a strategy for coping with disease, complementary and alternative medicine thus appears capable of enhancing the affect and well-being of persons with MND and their families, and hence helping them to find greater meaning in life as time progresses (Wasner et al., 2001).

#### **4.1.4.3 Extending Treatment Principles – Integrated MND Management**

While the decision on the part of patients to use complementary and alternative medicine clearly brings with it self-preservation and hope (Deverell et al., 2004; Newbury, 1991), the possibility also exists that at any stage during the disease process this hope can be destroyed. For example in the case of Unit 4, when the HCP told the person with MND and his wife not to waste their money pursuing stem cell therapy, both individuals felt that the little power that they did have in terms of trying to control the disease and change their future, had been taken away from them. Although the basis for this HCP's recommendation perhaps stemmed from the fact that at present there is equivocal evidence to support stem cell therapy in the treatment of MND (Oldendorf & Bruijn, 2004), for participants this suggestion reportedly signified a loss of hope and impaired their expectations for a better future. Notwithstanding this conflict of interest that therefore appears to exist between some patients and their HCPs, research has shown that the use of complementary and alternative medicine is on the rise (Ernst, 2002), with more and more healthcare consumers combining it within a conventional healthcare framework (Corner & Harewood, 2004 as cited in Richardson, 2004). On this basis, and the fact that most participants in this study echoed that they had "*nothing to lose*" by trying unorthodox treatments, it therefore seems apt that the next logical step in the management of MND might be to integrate alternative approaches with traditional medical and rehabilitative management, so as to develop one comprehensive intervention programme that maintains hope and provides quality healthcare to all persons with MND and their families.

In relation to the preceding example pertaining to Unit 4, a paradox is seen to arise for medical HCPs. Although anecdotal evidence supports alternative medicine in that it provides psychological support and a positive sense of well-being (Leigh et al., 2003),



there are some medical HCPs who are reluctant to recommend alternative treatments because quality data regarding the risks and benefits of such interventions are lacking (Caspi & Hoxha, 2005). Moreover in relation to the ethical principle of non-maleficence, some medical HCPs may in part practise according to the precautionary principle which states, “*We (i.e. HCPs) should refrain from action or of the implementation of new technologies, until there is reasonable scientific proof that such actions or technologies will not cause substantial harm to the environment or to man or other living beings*” (Ter Meulen, 2005:S664). In distinguishing non-maleficence from beneficence however, during clinical practice medical HCPs also have an obligation to act for the benefit of the patient (Ter Meulen, 2005). Consequently if medical HCPs choose to adopt the precautionary principle when considering alternative medicine for the management of MND, it is unlikely that they will recommend unorthodox treatments in view of the paucity of efficacy studies available (Leigh et al., 2003). However because the use of alternative medicine is reported to be of value anecdotally (Leigh et al., 2003), irony lies in the possibility that some HCPs may in fact be failing to benefit their patients by not condoning such interventions. Thus as in any clinical decision-making process, Ter Meulen (2005) recommends that HCPs must be knowledgeable of the benefits of various treatments as well as the possible burdens or harm. For medical HCPs this perhaps suggests that rather than feeling sceptical about complementary and alternative medicine, it is possibly time that they become more open-minded and broaden their knowledge of this healthcare paradigm. Furthermore because many patients use complementary and alternative medicine without informing their medical practitioner, and not all alternative treatments are risk-free (Ernst, 2002), it is essential that medical HCPs have adequate knowledge proficiency about alternative care so that irrespective of their own opinion, they can discuss this healthcare paradigm openly with their patients and their colleagues (Caspi & Hoxha, 2005; Klimenko & Julliard, 2007). Caspi and Hoxha (2005) therefore express that apart from the need for alternative professionals to become more knowledgeable about allopathy, medical HCPs need to be aware of emerging efficacy studies in alternative medicine, and be able to provide their patients with quality information about the safety and effectiveness of such interventions (Hsiao, Ryan, Hays, Coulter, Andersen, & Wenger, 2006; Richardson, 2004). After all increased knowledge between medical HCPs and alternative professionals will facilitate them in making prudent assessments about the benefits,

burdens, and harm of various interventions, thereby dispelling the potential for paradoxical scenarios and better equipping all practitioners to act in the best interest of their patients (Caspi & Hopley, 2005; Ter Meulen, 2005).

The importance of symmetrical knowledge and collaboration between medical HCPs and alternative professionals may also lie in the potential to prevent situations like one mentioned in this study, where the homeopath from Unit 2 informed the person with MND that she had been misdiagnosed. Although from his perspective and training the homeopath may have been justified in diagnosing the patient otherwise, collaboration between the two practitioners may have avoided unnecessary false hope for the person with MND and her family. In response to this example and the discussion on complementary and alternative medicine thus far, evidence therefore exists to support the merging of these two diverse modalities (i.e. traditional medicine and alternative medicine) into one integrated and comprehensive healthcare system (Hollenberg, 2005). Given that traditional medicine is based on reductionism, rationality, and a separation between mind and body, while alternative medicine focuses on non-reductionism, holism, and inseparability between health and illness, integrated healthcare is therefore viewed as the ideal because biomedical disease models are expanded to include the “wholeness” (mind/body/spirit) of patients in the healing process. Furthermore integrated healthcare also encourages a collaborative partnership between patient and practitioner, and in doing so renders a non-hierarchical, trusting, and respectful continuum of care (Hollenberg, 2005).

Since integrated healthcare therefore addresses both the physical and emotional sequelae of disease, as well as develops and sustains therapeutic relationships, allows individuals to take control of their own healthcare, and promotes a climate of philosophical congruence (Ernst, 2002, Richardson, 2004), a combination of traditional and alternative medicine appears to resemble closely a patient-centred approach to care. In light of the value that this study has placed upon patient-centred care, a further rationale thus exists for adopting an integrated healthcare approach for comprehensive management of MND that is possibly more congruent with healthcare consumers’ perceptions of quality care. However because the key to integrated healthcare lies in effective communication between all practitioners (Klimenko, Julliard, Lu, & Song, 2006), and the findings of this study demonstrated that

collaboration between even medical HCPs alone was limited, a challenge now rests with researchers and clinicians to find ways of engendering open-mindedness and creating working relations between all medical and alternative practitioners that will support co-management and therefore yield quality healthcare (Hsiao et al., 2006; Richardson, 2004). In addition by engaging in integrated MND management, healthcare consumers might not only experience hope for the future and a sense that they have “*everything to gain*” from receiving a combination of traditional and alternative medicine, but also persons may be saved the trouble of “playing” alternative medicine up against biomedicine in an attempt to find “the better deal”.

Finally it is thus evident that although complementary and alternative medicine is similar to allopathic healthcare in that it is unable to provide a cure for MND, it is nonetheless an attractive paradigm because of its “whole person orientation” and the fact that patients are provided with support and empowered to engage in their own healthcare (Shinto et al., 2005). In addition features of alternative medicine also have the affective capacity to foster enhanced patient-professional relationships and make a difference to healthcare consumers’ lives by engendering hope for the future (Klimenko et al., 2006; Shinto et al., 2005). Moreover despite some medical HCPs’ paradoxical stance and scepticism regarding complementary and alternative medicine in view of its small evidence base (Caspi & Holexa, 2005; Ter Meulen, 2005), as well as the fact that the principles of this approach are removed from a biomedical framework of practice (Hollenberg, 2005), an alternative healthcare paradigm appears of value in the management of MND because it is conducive to patient-centred care and creates opportunities for patient-centred communication. Thus by accepting complementary and alternative medicine as part of the management of MND, as well as encouraging medical HCPs to learn from alternative professionals and vice versa, the possibility exists for rendering health communication and management that is more compatible with individuals’ perceptions of acceptable MND healthcare. Through a supportive climate of collaborative research, training, and education (Richardson, 2004), both medical and alternative professionals are therefore able to play a significant role in instilling reasonable hope and ensuring the best possible holistic care for persons with MND and their families.

#### **4.1.5 Bioethical Practice**

In recent years controversial and troubling issues relating to healthcare have received significant attention, to the point that there has been rapid expansion in the study of biomedical ethics so as to ensure that HCPs uphold the highest standards of integrity, and professional and clinical practice (Strand, 2003; Strand et al., 1998). Ironically despite this growth however, reports of general patient dissatisfaction with treatment that is received and/or the manner in which HCPs treat their patients (Fossum & Arborelius, 2004), suggest that the ethical and moral concerns pertaining to healthcare have possibly become a forgotten keystone of professional practice (Hunt, 1991). In particular the care of terminally ill individuals is an area of healthcare that is often fraught with ethical challenges, especially when persons present with diminished cognitive capacity (Brady Wagner, 2003). However even in the presence of relatively intact cognition, the results of the present study revealed that the management of MND is also overcome by significant ethical concerns, and if one hopes to enhance the quality of care rendered to this patient population then these issues must surely come under the spotlight.

With respect to principle-based bioethics, it was established in this study that almost all major and minor bioethical principles were violated, with some principles being in conflict with one another and giving rise to various ethical problems (Beauchamp & Childress, 1994). Typically discussions surrounding bioethics, of which there is evidence in the speech-language pathology literature, involves an author presenting a hypothetical case that encompasses a specific ethical problem. The various hierarchical levels of moral justification are then discussed, as well as the bioethical principles that are in operation and the ethical problems that may arise as a result of conflict between different principles and rules. Whilst Gillon (1985) suggests that this type of ethical analysis provides an acceptable basis for establishing more rigorous answers to various ethical problems, because the nature of ethics is very subjective and there are frequently no right or wrong answers (Strand, 2003; Strand et al., 1998), these types of discussions can run the risk of authors merely presenting their personal interpretation of a situation. For the purpose of the discussion that follows therefore, the researcher has chosen to avoid presenting different scenarios and conflicting bioethical principles that arose in the study, with the view that one example after the next would merely provide a subjective analysis of the findings,

yielding no further value in terms of effecting change in the management of persons with MND. Rather only the most pertinent ethical issues such as decision-making, medical futility, and professional and ethical conduct are discussed. Reliability of the discussion is further enhanced by virtue of the fact that these topics also came under scrutiny of the focus group. In addition a new bioethical perspective is considered, which may be more in line with the inherent needs specific to the medical and rehabilitative management of persons with MND and their families.

#### **4.1.5.1 Decision-Making**

Since there is no *prima facie* reason to suggest that HCPs are in a better position than their patients to make decisions about a course of action to be followed (Gillon, 1985), ethicists no longer agree that because the physician's primary function is to make the patient feel better, a certain amount of authoritarianism and domination is acceptable (Ingelfinger, 1980 as cited in Gillon, 1985). Even in terms of technical medical aspects the argument for patient ignorance is suspect, in view of the fact that HCPs should be able to explain such technical medical details to their patients in a satisfactory manner (Gillon, 1985). Respect for patient autonomy is thus a core ethical construct, and it is often regarded as morally supreme if human welfare is to be truly maximised (Gillon, 1985; Macciocchi & Stringer, 2001). As a result, since patient decision-making within the realm of healthcare is a fundamental yet complex endeavour, if one is to avoid authoritarianism and instead respect the patient's right to determine his/her own destiny, the interplay of factors that govern decision-making need to be considered (Bliss & While, 2003).

According to Leigh et al. (2003) the management of MND should emphasise autonomy and choice, and individuals with the disease should be provided with sufficient opportunities to make informed decisions about intervention and terminal care. HCPs also need to ensure that patients act intentionally, with understanding and without coercion (Beauchamp & Childress, 1994). Moreover because the nature of MND is such that many decisions need to be made regarding the individual's future (Francis et al., 1999; Leigh et al., 2003), it is essential that the person with MND is included in detailed discussions with the various members of the Unit, in order to evaluate all possible decision-making options (Leigh et al., 2003). In the case of the present study however, irony exists in the sense that despite the need for such detailed

discussions, many HCPs reportedly avoided conversations about long-term management of the disease, and the majority of participants therefore had few decisions to make about different interventions and their future. In addition because some participants were informed that nothing could be done for the plight of persons with MND, the decision-making process for these individuals was yielded “unnecessary”. Moreover even in instances where participants read on the Internet about the progression of MND and demonstrated an awareness of issues such as the potential for alternative feeding, some nonetheless downplayed their symptoms and stated that they would withhold making decisions for as long as possible because their HCPs had made no reference to such options. They further stated that they were uncertain as to how one comes to conclusions of this magnitude without professional guidance. Consequently this lack of professional involvement and guided patient self-determination can perhaps be construed as a paternalistic attitude on the part of some HCPs where, “*An action is taken by one person in the best interests of another without their consent*” (Thomasma, 1983:244). Although one could however refute the argument for medical paternalism in this study because HCPs did not verbally deny participants access to different interventions for example, the fact that such options were never raised for discussion might imply that some professionals acted on behalf of their patients, and made decisions for them (e.g. withholding of rehabilitation) based on their personal beliefs or position of authority. Failure to engage in a collaborative decision-making process thus raises questions as to whether HCPs in this study were in fact acting in the best interest of their patients, and whether the right to self-governance, free will, and choice was held paramount to the healthcare encounter (Bach, 2003; Macciocchi & Stringer, 2001).

In accordance with theories of decision-making, a paternalistic approach falls within a prescriptive model, whereby the HCP leads and the patient follows. Any decisions to be made are prescribed by the HCP to the patient, and they always result in the same conclusion regardless of who makes the decision, because each individual’s unique context is not considered (Bliss & While, 2003). By virtue of individual variability that is inherent to the healthcare encounter (Swenson, Zettler & Lo, 2005), each patient’s individual situation and need for holistic management should however be recognised. A prescriptive model of decision-making in such instances is thus contraindicated. Rather Beach (1997 as cited in Bliss & While, 2003) suggests the

appropriateness of behavioural theories of decision-making, where judgements are reached on the basis of multiple sources of data that are assessed and synthesised simultaneously. Moreover it is held that decisions should be based on each patient's personal needs and not the HCP's intellectual convictions, and that no decisions should be taken in the best interest of the patient without his/her consent. Mutual exchange must therefore occur between the patient and the practitioner, allowing the patient the freedom to direct his/her own life in as far as possible (Bach, 2003; Ross & Deverell, 2004g; Thomasma, 1983). In the case of MND the opportunity for self-governance and free will is of paramount importance, because not only do competent adults have a right to determine their course of medical care, but also studies have shown that individuals with this disease readily express their wish to participate in the decision-making process (Silani & Borasio, 1999; Silverstein et al., 1991). Thus, in line with the right to self-determination and a corresponding ethical obligation for HCPs to promote and sustain the autonomy of their patients (Silani & Borasio, 1999), the use of behavioural theories of decision-making may perhaps be of value in terms of the management of MND.

The general process of providing patient autonomy is not however a simple task. Firstly healthcare consumers are often vulnerable in the face of life-changing events, and need to be guided and protected to a certain extent. Secondly by virtue of their knowledge of disease and treatment, HCPs have an epistemic authority over patients such that in one sense it is almost advisable that healthcare consumers defer to this authority (Hayry, 1991 as cited in Ross & Deverell, 2004d; Ross & Deverell, 2004d). As a result, Bliss and While (2003) suggest that it is important to consider the exact processes that are involved in decision-making, because in many instances it is unclear what constitutes a "correct" decision, especially when considering decisions surrounding terminal care and continuing care needs during a limited life trajectory. Dean and Sharfman (1996) thus propose a multi-layer framework that accounts for the multiple variables involved in the decision-making process. The rationale behind applying this four layer framework to the management of MND, is such that by analysing the key components involved in the decision-making process in terminal care, areas of weakness may be revealed which might help one to better understand the basis of participants' perceptions with regard to a lack of autonomy and free will. More so an improved understanding of the decision-making process may also

facilitate HCPs in rectifying such breakdowns, so as to ensure improved autonomy and patient self-determination.

The first key component central to the decision-making process is procedural rationality, or the collection and analysis of data to inform choice (Dean & Sharfman, 1996). In other words, the decision-making process relies on the exchange of information in order to guide patients and HCPs towards plausible decisions (Ross & Deverell, 2004d). As reported in this study however, a paucity of information transfer was perceived, and when examined more closely two possible issues arose in terms of the exchange of information that may have affected decision-making. Firstly, issues relating to information and decision-making may have arisen as a result of the behaviour of persons with MND and their families. As documented throughout this study, the emotional nature of MND may have hindered individuals from processing, understanding, and/or retaining information provided by HCPs. Thus whilst HCPs may have tried to engage in discussion to facilitate informed decision-making, participants may have felt too overwhelmed at the time to process given information and act upon it.

Secondly because of the multifaceted nature of MND (Leigh et al., 2003), HCPs need to be well informed about the different interventions, services, and support organisations that are available for MND management. When HCPs have this knowledge they can then engage in discussions with healthcare consumers, informing them of the facilities at their disposal and facilitating them in making informed decisions about their future. However as demonstrated in the present study, such discussions did not occur albeit because some HCPs were possibly unaware of the needs of persons with MND, uninformed regarding available healthcare services, or simply sceptical about referring patients for certain interventions that have not as yet revealed their full efficacy. Although at first glance this behaviour on the part of some HCPs might thus be viewed as paternalistic, it is also possible that these individuals were in fact trying to act in the best interest of their patients by avoiding the recommendation of services that may have been potentially harmful or of little benefit to healthcare consumers. Consequently it is possible that these HCPs were practising from a teleological perspective, whereby their actions (e.g. failure to refer for intervention) were based on whether or not the consequences (i.e. intervention that



has demonstrated a positive outcome) would be perceived as acceptable or unacceptable (Seedhouse, 1998). However, regardless of whether or not HCPs made a conscious decision to act from a teleological perspective, their lack of knowledge regarding available services for MND management or their choice to withhold such information from patients, nonetheless affected the decision-making process. Moreover because participants were neither provided with information pertaining to different interventions and support organisations, and nor were they informed about important life decisions that would need to be made in the future, HCPs were perceived as deceiving their patients and being untruthful. To this end violation of the ethical principle of fidelity or the keeping of promises is evident (Strand, 2003; Strand et al., 1998). Finally, the fact that some participants felt deceived and were denied access to collaborative decision-making may have resulted in either physical and/or emotional harm being experienced. Thus the HCP's obligation to engage in non-maleficent behaviour and refrain from harming his/her patient may have also been breached (Strand, 2003; Strand et al., 1998). In essence therefore, irrespective of whether the breakdown in procedural rationality arose from patient-specific and/or professional-specific sources, this component of decision-making and the individual's right to autonomy was compromised in this study, such that persons with MND and their families reported experiences of deception and harm.

The second key component in Dean and Sharfman's (1996) decision-making framework is political behaviour, or the influence of professionals and organisations on the decision-making process. Since the majority of participants in this study reported having made few decisions about their future, HCPs and organisations appeared to have minimal influence in this regard. However one particular instance did arise that is worthy of discussion, so as to illustrate how powerful and possibly even harmful some HCPs can be if they exert too much control on the decision-making process. In the case of Unit 6, the daughter reported that she was strongly against her mother being ventilated when the time arose, because the doctor had informed her that it is a part of life that should not be prolonged. When questioning the person with MND about this issue however, she was reluctant to discuss the matter with the researcher and did appear less adamant about the decision in comparison to her daughter. Although it is reasonable to assume that this reluctance may have related to the person with MND feeling too overwhelmed to discuss issues

of life and death, the literature suggests that one should not overlook the fact that during times of serious illness or disease, relatives often adopt a paternalistic and controlling attitude in an attempt to cope with their own emotional difficulties (Pucci et al., 2003). According to Pucci et al. (2003) therefore, in many instances it is the relative's choice about future medical care that is likely to prevail over the patient's autonomy. Hence in Unit 6 it is possible that the decision to withhold ventilation may have been based on the HCP or the daughter's opinions and influence, rather than on what the person with MND would have preferred for the final stages of her life.

In terms of the rationale that the HCP from Unit 6 provided with regard to the withholding of ventilation, a further concern relates to professionals who give advice rather than sound information upon which healthcare consumers can make informed decisions. A statement such as, "*It is a part of life that should not be prolonged*", possibly represents this HCP's personal opinion about life and death, and the fact that if he were in a similar situation he would prefer not to be ventilated. Contrasting this personal opinion however, empirical evidence demonstrates that more than 90% of ventilator-dependent persons with MND/ALS want to live despite total physical dependence and the need for continuous ventilatory support. Furthermore, these individuals state that they would not change their decision for ventilation if they had the chance again (Bach, 1993; Gelinas, O'Connor & Miller, 1998; McDonald, Hillel & Wiedenfeld, 1996; Moss et al., 1996). Hence it is imperative that patients be encouraged to direct their own lives and make their own informed decisions, because too often a patient's attitude about ventilation reflects that of his/her HCP (Bach, 1993). In the presence of self-determination there is also a need for patient choices to be reviewed on a regular basis. Review helps to safeguard patient autonomy because persons with MND often change their decisions about life-sustaining interventions several times during the disease process, especially as they experience progression of disability, change in their perceived quality of life, and change in their perceptions about the benefits and burdens of different therapies (Francis et al., 1999).

A further aspect of how the opinions of HCPs might impact on the decision-making process relates not only to what they may say to patients, but also the timing of what is said. In the case of Unit 2, the person with MND was not warned in advance about the possible need for a percutaneous endoscopic gastrostomy. It was only once she

began experiencing swallowing difficulties and the representative from the MND Association of South Africa was contacted, that she was referred to a surgeon who conducted the procedure soon thereafter. In such instances persons have little time to contemplate their decisions and may be rushed into making choices which might not only be in disagreement with their personal values and preferences, but they may also regret such decisions at a later stage. It is thus incumbent upon HCPs to guide patients in the decision-making process, by providing timely assistance that is based on clinical expertise and an understanding of individual preferences irrespective of personal bias (Goldblatt, 1992 as cited in Francis et al., 1999). Finally one should also consider that in the context of MND management, a team approach may provide more than just appropriate interventions, it may in addition act to safeguard the decision-making process further. Since a team offers patients more than a single HCP with whom decisions can be discussed, opportunities for bias and deception may be reduced (Bach, 2003; Bliss & While, 2001). Hence collaborative team discussions are essential in the decision-making process, as they may regulate political behaviour by reducing the involvement of overly influential HCPs, whilst simultaneously guiding patients and their families in the direction of informed yet unbiased decisions.

The environment and the manner in which it supports the decision-making process functions as the third component of Dean and Sharfman's (1996) proposed framework. Findings throughout the present study revealed that the environment of persons with MND and their families was characterised by minimal support. The fact that persons with MND were not provided with follow-up appointments for example, and that some participants perceived dissatisfaction and limited access in terms of support organisations, meant that individuals lacked the informational and emotional support required to aid the decision-making process. Failure to achieve such a supportive environment is also likely to have contributed to a lack of beneficence or the doing of good for other people (Gillon, 1985), given that some participants in this study reportedly experienced a sense of abandonment and neglect by their healthcare providers. Moreover since technology is another environmental variable that can influence the decision-making process (Dean & Sharfman, 1996), the use of the Internet may have further affected the decisions of persons with MND and their families. As confirmed by the majority of participants, the Internet was a major source of informational support and many individuals relied on it to learn more about

MND and its management. However unlike a study reported by Eysenbach (2003) where 92% of patients with cancer believed that the Internet empowered them to make decisions, several participants in this study claimed to be aware of the major decisions that needed to be made, but were reluctant to arrive at any conclusions without professional guidance. While the Internet is thus a potentially positive factor in the healthcare process, it is also possible that due to the magnitude of the decisions that persons with MND need to make, a human interface is required to facilitate these individuals in this regard. Hence the use of the Internet in healthcare cannot be viewed as a substitute for the patient-professional relationship, as it cannot offer the ideal of personalised communicative exchanges that are characterised by the warmth, reassurance, and the guidance necessary for facilitating decision-making.

The media and its promises is another environmental influence that is worthy of consideration. In society it is common knowledge that false advertising or offers devoid of sound evidence, may be used by marketers to lure hopeful consumers toward a particular product. And in the healthcare arena similar practice may be no different. This reality coupled with the fact that desperate healthcare consumers are often willing to pursue any avenue in order to find a cure or the possibility of hope, means that some participants in this study may have been easily tempted into investigating various healthcare options that are not yet necessarily scientifically proven. In addition, the literature also suggests that the emotional and psychological sequelae of extensive disability may compromise an individual's ability to evaluate the risks and benefits of various treatments, such that the chance of a patient understanding in full the implications of a decision to undergo or reject treatment is remote (Foye et al., 2002). The challenge for HCPs therefore lies in the manner in which they direct vulnerable patients toward novel treatments, and deal with ethical concerns which may arise. For example in the case of Unit 4, the fact that the HCP told participants not to waste their money investigating stem cell therapy may have been justified, given that there are presently many uncertainties surrounding the use of stem cells to replace motor neurons (Oldendorf & Bruijn, 2004). In other words the HCP may have been trying to prevent the person with MND and his wife from experiencing a potentially false sense of hope, as well as from investing a large sum of money which in the end may have yielded minimal benefits. Whilst thus acknowledging that this HCP was perhaps attempting to uphold the principle of non-

maleficence, concern arises in that the person with MND and his wife were merely informed by the practitioner that they should not waste their money. No rationale for this recommendation or further discussion surrounding stem cell therapy was provided. Based on such occurrences, Slowther, Ford and Schofield (2004) suggest that apart from HCPs using evidence-based medicine to inform their own clinical judgement, in order for patient autonomy to be respected, evidence-based practice must in fact include the use of evidence in discussions between patients and professionals about decisions that need to be made. In the case of Unit 4 therefore, despite the Internet informing participants about the potential risks and benefits of stem cell therapy, and the HCP having perhaps formulated his own opinion about this treatment based on academic reports, it is likely that a more positive decision-making process may have been perceived had the practitioner provided the person with MND and his wife with sound information and proof about stem cell therapy and its relation to the management of MND.

In addition to providing the facts so that patients can make informed decisions, the example presented here in terms of stem cell therapy also raises questions with regard to veracity. Since veracity relates to truth-telling and insists upon a patient-professional relationship founded on honesty, integrity, and truthfulness (Ross & Deverell, 2004g), it is possible that by not telling the person with MND and his wife about the risks and benefits of stem cell therapy, a violation of this principle may be construed. Although the importance of veracity cannot be denied, the application of truth as an obligatory principle is often unclear. HCPs often cannot speak in terms of absolute or whole truth because in most cases they do not know what will happen to the patient as time lapses (Hunt, 1991). Consequently as in the case of Unit 4, although the HCP was seemingly opposed to stem cell therapy, it is also fair to say that he may have been unsure as to whether or not the treatment would have been of value to the person with MND. Furthermore given that truth-telling has the potential to undermine hope that the disease will regress or that treatment will result in a cure (Hunt, 1991), by offering the person with MND and his wife all the facts about stem cell therapy, the HCP may have destroyed their hope. In essence HCPs are therefore placed in a no win situation: if they acknowledge the principle of veracity and tell the truth they may be criticised for destroying hope, yet if they choose to withhold the full truth, principles such as non-maleficence and fidelity may be undermined.

Whilst it is thus clear that the environment has the capacity to alter the decision-making process in either a positive or negative manner, it is ultimately the response of patients and HCPs to these environmental variables that may or may not instil a sense of support regarding decisions that are to be made. Moreover because of patient variability, individual needs, preferences and values, a supportive environment and respect for autonomy may not be perceived in the same light by all healthcare consumers. Transformations in bioethics therefore suggest that facts known only to HCPs should be supplemented by values and needs specific to each patient (Sullivan, 2003). And hence in reiterating the value of patient-centred care the patient's point of view is again highlighted, not only for facilitating HCPs in establishing an environment that suits each patient and supports the decision-making process, but also for acknowledging that within this environment exists a patient and his/her individual right to autonomy, choice, and self-determination.

The fourth and final component of the decision-making framework relates to the quality of implementation, and focuses on the steps taken to reach a decision (Dean & Sharfman, 1996). Quality decision-making is also based on the patient and his/her family being a part of the team (Clark & Seymour, 1999 as cited in Bliss & While, 2003). As demonstrated in the present study, decision-making as a team did not occur. Not only were MND treatment teams non-existent, but also many HCPs lacked involvement in MND Units and played a limited role in the management of the disease and the making of decisions. With regard to decision-making that occurred between persons with MND and their families, some family members did appear to influence the decision-making process, although variation was noted across Units. For example, unlike Unit 4 where the wife felt that because her husband was the one affected by the disease and should therefore control the decisions made about his future, in Unit 3 the person with MND and her husband both reported making joint decisions. Such differences between Units are expected because the degree to which family members are involved in the decision-making process not only varies across families, but is also based on relational autonomy and the fact that persons are defined by their familial relationships and therefore influenced differently by family members when making decisions (Öhlén, Balneaves, Bottorff & Brazier, 2006). Notably however, because the aim of this study was not to investigate the family dynamics involved in decision-making in MND, the topic has not been discussed further

although implications do nonetheless arise in terms of future research. Since most studies which investigate decision-making in MND focus on issues surrounding life support and ventilation, it is perhaps time for research to begin determining how members of the Unit make and sustain decisions about medical, rehabilitative, and alternative management. Such an understanding may assist researchers in developing a model of decision-making specific to MND, which can be used by HCPs to facilitate the process in terms of negotiating mutually acceptable roles for making decisions, and acknowledging healthcare consumers' rights to autonomy and self-determination. From the perspective of HCPs, future research may yield value by investigating how HCPs self-evaluate their abilities to engage in collaborative decision-making. Results may assist researchers in developing training programmes that can be used to facilitate HCPs to incorporate patients and their families in the decision-making process, while simultaneously ensuring respect for autonomy, providing opportunities for quality decision-making, and thus instilling an overall environment conducive to self-determination and choice.

Finally in terms of the quality of decision-making it is clear that breakdown occurred at each level of Dean and Sharfman's (1996) framework, thereby compromising the overall decision-making process for persons with MND and their families. Furthermore such compromise undermined many of the bioethical principles, and most of all denied several participants their right to autonomy, free will, and choice with regard to determining their own future. Given however that decision-making is just one aspect of bioethical practice, decision-making frameworks such as the one presented by Dean and Sharfman (1996) perhaps need to be extended to incorporate variables that place the decision-making process within a broader context of ethical healthcare. One variable that cannot be omitted from either healthcare in general or the decision-making process is that of communication, given that it appears to underlie every component in Dean and Sharfman's (1996) framework as well as mediates the multiple variables involved in order to achieve an effective outcome or decision. In other words for example, successful decision-making relies on the success of information exchange between the patient and the professional, so as to provide opportunities for informed self-determination and choice (Arora, 2003; Bruera, Sweeney, Calder, Palmer & Benisch-Tolley, 2001). Moreover in the case of terminal illness, because patient-professional communication is usually made more

difficult by the fact that some patients may neither “hear” nor appreciate that which they are told (Cimino, 2003), the consideration of communication in a decision-making framework is especially important. Without awareness of a patient’s specific communicative needs and the appropriate use of communication to meet these needs, the decision-making process runs further risk of breakdown at any level. Consequently for persons with MND, because it was demonstrated in this study that a mismatch existed between participants’ communicative needs and that which was delivered by HCPs, it is of little surprise that breakdowns were evident at various levels of the decision-making process. More so with respect to the communication impairment, had persons with MND been more able to achieve effective communication with HCPs, and HCPs been better equipped to meet their patients’ communicative needs, it is possible that participants may have felt more communicatively empowered to achieve successful informational exchange necessary for informed decision-making and subsequent autonomy. In addition had HCPs adopted a patient-centred communication approach, participants may have experienced a further sense of empowerment, and the overall quality of the decision-making process in this study may have been perceived as more satisfactory.

In conclusion it is thus evident that adequate decision-making is founded upon a supportive and trusting environment that is characterised by reciprocal communication, demonstrates unconditional positive regard, and acknowledges the patient’s perceptions of his/her experience of illness. In other words, factors such as patient-centred care and patient-centred communication appear to be important variables for establishing and mediating a more successful decision-making process. The overlap between bioethical practice, patient-centred care, and patient-centred communication as depicted in Chapter 1 is thus reiterated, highlighting that in the presence of adequate decision-making and hence satisfactory bioethical practice, high quality healthcare is not likely to be perceived unless patient-centred care and patient-centred communication are of a similar standard.

#### **4.1.5.2 A Case of Medical Futility**

Although HCPs have an ethical responsibility to deliver services to all healthcare consumers (Hunt, 1991), one of the most alarming findings of the present study was the fact that many persons with MND failed to receive and/or were not referred for



intervention. In view of the status of South Africa's current healthcare system and its lack of resources (Ross & Deverell, 2004a), readers might be hasty to assume that this finding was a result of limited access to available healthcare facilities. Since all participants in this study lived in urban areas however, and at the time of data collection many belonged to a Medical Aid, issues regarding funding and accessibility to healthcare were not fundamental to this discussion. Rather one perhaps needs to consider whether factors relating to treatment futility or ineffectiveness might explain the reason for the poor referral rate and lack of involvement in intervention depicted in this study.

According to Wreen (2004) some patients have no chance of survival if treatment is not received, and only a small chance of surviving if treatment is implemented. In such cases treatment is believed by many physicians and medical ethicists to be medically futile, or useless and ineffective. As claimed by Brody (1994 as cited in Wreen, 2004) in his earlier work, in these instances physicians need not consult the patient and/or family to determine their preferences about withholding treatment, because such a decision should be made at the professional's own discretion, and professional integrity should dictate that treatment should not be pursued. Presently however, controversial medical issues such as resuscitation and aggressive nutritional intervention question whether HCPs are uniquely qualified to make decisions on behalf of patients and family members. Medical futility or the withholding of treatment because it reportedly will not benefit the patient, is therefore discussed most commonly in the context of life and death decisions (Cimino, 2003). However it is possible that certain interventions could be deemed as medically futile depending on whether or not in the case of terminal illness they promote quality of life.

In the present study, the fact that several HCPs failed to refer persons with MND for intervention and told them that nothing could be done to help them, possibly suggests that these professionals viewed available treatments for MND as failing to enhance quality of life and therefore medically futile. In opposition to this view, whilst the concept of medical futility implies that treatment will not help, Cimino (2003) states that one must ask themselves the question, "*Will not help what?*" Since one of the primary goals in the management of MND is to enhance quality of life (Leigh et al., 2003), by denying individuals intervention because it supposedly "*does not help*",

HCPs are perhaps implying inadvertently that treatment will not address the patient's quality of life. However, the implications of such a rationale are problematic because quality of life issues involve value judgements that are not necessarily objective and are different for each individual concerned (Cimino, 2003). HCPs therefore do not have the authority to judge the quality of life of their patients, as their subjective judgements are likely to be based on the general population and may be inaccurate and unwarranted in the context of individual management decisions (Bach, 2003; Sullivan, 2003). Furthermore although the American Medical Association Code of Medical Ethics (1997 as cited in Cimino, 2003) states that physicians are not ethically obliged to provide services that based on professional judgement will not have a reasonable chance of benefiting patients, improvements to a patient's quality of life are difficult to predict. More so because patients and/or family members experience a significant amount of stress when they are denied treatment that they believe will produce a positive outcome (Cimino, 2003), decisions made by HCPs to withhold intervention that they believe to be inappropriate could in fact result in psychological harm for the patient. Thus whilst by no means suggesting that HCPs should prescribe any treatment to a patient regardless of proven benefits, one must consider that if the various interventions for MND are denied on the grounds of perceived medical futility, then not only are individuals denied an opportunity to potentially improve the quality of their life, but also their hope for the future is destroyed given that medical futility and hope are intrinsically related (Cimino, 2003). HCPs therefore need to realise that because it is the patient's life to lead, when the possibility exists for improved quality of life and the patient wishes to pursue it, such decisions (e.g. a referral for rehabilitative management) should not necessarily be trumped by a concern for medical futility or professional integrity (Wreen, 2004).

#### **4.1.5.3 Professional and Ethical Conduct**

According to Cornett (2006) professionalism is evident in successful clinical practice and is demonstrated through the attitudes, knowledge, and behaviours of HCPs. Irrespective of these attributes characterising acceptable clinical practice however, and HCPs having an ethical responsibility to engage in professional behaviour, worldwide healthcare personnel and organisations are being criticised by the public regarding their professionalism (Cohen & Gabriel, 2002; Cornett, 2006). Consequently in the present study, apart from variables such as medical futility and

limited efficacy studies preventing persons with MND from receiving referrals for intervention, it is possible that questionable behaviours on the part of various HCPs may have also been a contributing factor. In considering the widespread dissatisfaction that patients report in terms of healthcare service delivery, HCPs are urged to re-examine their fundamental commitment towards the welfare of their patients (Cohen & Gabriel, 2002). Thus with a view to improving the medical and rehabilitative management of MND, by revealing some of the questionable professional behaviours evident in this study, areas in need of change, recommitment, and patient advocacy may be highlighted.

Two examples from the present study are used to illustrate and examine the appropriateness of various professional behaviours. Firstly in the case of Unit 1, the person with MND reportedly attended a physiotherapist who stated that she knew nothing about MND, although she was nonetheless prepared to provide treatment. While it is entirely acceptable not to know about MND, and HCPs are not expected to know about all disorders (Cornett, 2006), the problem arises in that professionals have an ethical injunction to treat only those disorders for which they are trained and competent, and from which the patient can benefit (Cimino, 2003). Plainly speaking, Cornett (2006) states that HCPs have to know what they are doing and demonstrate their professionalism. On this basis one would therefore think that if a HCP does not know about a specific condition, common sense would dictate that the patient be referred to a more suitable colleague. Should referral not be possible because of limited resources however, then treating the patient and charging for services rendered should not occur until such time that the professional has developed an adequate knowledge base of the condition, and can formulate a reasonable treatment plan.

The second example pertinent to this discussion, relates to the speech-language pathologist in Unit 1 who stated that nothing could be done to help the person with MND. In view of this statement it is possible that this speech-language pathologist really did believe that nothing could be done for the individual, and hence it is likely that she too had limited knowledge in terms of how one should intervene. In one sense it is possible that this belief may in fact have benefited the participant, because had the speech-language pathologist tried to treat the person with MND it may have resulted in more harm than good. After all the Code of Ethics for Speech-Language

Pathologists and Audiologists presented by The South African Speech-Language Hearing Association (SASLHA, n.d. a), states that therapists should only treat patients if they hold the appropriate qualification and are competent in their actions. Furthermore given that this particular person with MND claimed to be experiencing swallowing difficulties when consulting the speech-language pathologist, the fact that no intervention efforts were adopted meant that amongst others, the bioethical principles of beneficence and non-maleficence were violated. Moreover because the person with MND was given inappropriate information about speech-language pathology intervention and was mismanaged, the principle of veracity was also undermined. In terms of justice, because no referral was made to a suitable colleague the person with MND was further denied access to acceptable healthcare, despite the fact that all persons with a communication disorder have a right to receive the necessary health services (SASLHA, n.d. b). Failure therefore to uphold the fact that referral and networking are an ethical responsibility, as well as to omit this from clinical practice, means that a significant component of effective patient care is also omitted. Finally one needs to consider the knowledge that speech-language pathologists possess with regard to brain behaviour, pathophysiology, and the neuropsychological processes that underlie communication (American Speech-Language Hearing Association [ASHA], 2005). Even if the speech-language pathologist in question knew nothing about MND, at the very least her intuition should have guided her in terms of the fact that the presence of some type of neurological disruption has the capacity to give rise to a communication and/or swallowing impairment, thereby heightening the need for speech-language pathology intervention.

A further factor relating to professional and ethical conduct is that of distributive justice. According to Purtillo (1993) distributive justice is concerned when more than one group of individuals compete for the same resources, and when one needs to determine the best criteria upon which to base resource allocation decisions. For example if a health service was to offer intervention for either ten children with language delay, or two patients with MND who would consume approximately 60% of the healthcare personnel's time, then it is likely that the ten children being the majority, would be given preference. More so anecdotally, one participant from the focus group reported that some speech-language pathologists have even stated that it

is unethical for therapists to waste their skills treating difficult neurological conditions when there is certainty that such patients “will die anyway”. In terms of distributive justice and the fact that healthcare funders may perceive it to be more valuable to invest in ten children and ultimately the opportunity to improve their future, one might therefore agree that persons with neurodegenerative conditions who have already experienced the prime of their life, need to take a “backseat” with regard to the allocation of resources. However the counter-agreement to this rationale lies in the fact that not only are healthcare providers unauthorised to judge the quality of life of healthcare consumers (Sullivan, 2003), but also societies such as the South African Speech-Language Hearing Association are committed to ensuring accessible and appropriate services for all persons with a communication disorder (SASLHA, n.d. b). Moreover because the Association’s Code of Ethics states that speech-language pathologists are not permitted to engage in discrimination on any basis (SASLHA, n.d. a), individuals with neurodegenerative conditions who do present with communication and/or swallowing disorders cannot be omitted from receiving intervention. Also, whilst just or impartial distribution of benefits and burdens implies a fairness towards patients, it does not necessarily mean an equal distribution (Purtillo, 1993). A conflict thus arises in terms of distributive justice versus patient advocacy. However with regard to justice and advocacy in speech-language pathology, it is not merely a case of justifying why one group of individuals who are communicatively impaired should receive greater access to resources than another group. Rather it is perhaps time to engage discussion at a deeper level and question speech-language pathologists about their obligation to advocate for the communicatively impaired population. Although there are many individuals around the world who experience disability of some type and rely on various HCPs to advocate for their rights, in a sense speech-language pathologists have a greater role to play for the communicatively impaired population in that they need to act as the voice for many of these individuals. Whilst the role of advocate and serving as expert witness is therefore an important one for speech-language pathologists to adopt (ASHA, 2005), many therapists appear to have failed both their patients and the profession in this regard. More specifically as demonstrated by the results of this study, the lack of appropriate management for persons with MND implies that all HCPs need to place greater emphasis on advocating for the rights of this patient

population in terms of gaining equitable access to resources and quality healthcare services.

In terms of the South African Speech-Language Hearing Association Code of Ethics, therapists are responsible for their professional behaviour towards patients, society, colleagues and the profession, as well as the advancement of knowledge (SASLHA, n.d. a). Implications thus arise in terms of patient advocacy relating to each of these levels of professional behaviour. For example at the level of the patient, speech-language pathologists need to advocate for healthcare consumers' rights, and ensure that individuals with MND and other neurodegenerative conditions are not discriminated against by virtue of inadequate resource allocation and the low incidence of such conditions. Furthermore, therapists who wish to practise in this area of speech-language pathology need to be knowledgeable and competent, and participate in appropriate continuing professional development.

At the level of society, speech-language pathologists need to market their services and educate other HCPs about the communicative and swallowing needs of persons with MND, as well as the role of the profession in this area of practice. Moreover because speech-language pathologists are clearly being omitted from the MND referral network, therapists need to investigate the reasons behind this finding, and endeavour to make the necessary changes in order to ensure that persons with this disease are not denied the services that they require. Also, by establishing a position within the referral network and strengthening working relations with colleagues, HCPs as a group may be able to advocate for more appropriate MND management facilities (e.g. MND clinics or clinics for persons with neurodegenerative conditions in general) by campaigning to healthcare funders. Legislative advocacy at a local, regional and national level could also be pursued.

In terms of responsibilities towards colleagues and the profession, therapists need to respect their colleagues and acknowledge that a preference for one area of speech-language pathology as opposed to another is not a sign of weakness or a waste of skill, but rather a strong commitment towards a particular communicatively impaired sub-population. Furthermore rather than criticising colleagues and regarding their work as of lesser importance, all speech-language pathologists might spend this time and energy examining their own therapeutic efforts and ensuring that they are

efficacious and effective. Regardless of the communicatively impaired sub-population with which one chooses to work, speech-language pathologists nonetheless have a responsibility to ensure their competency so as not to reflect adversely on the profession, and give patients and/or HCPs reason to question the value and integrity of speech-language pathology services.

Finally with regard to the advancement of knowledge, although literature pertaining to some degenerative conditions may be limited in relation to other areas of speech-language pathology, many of these disorders are nevertheless well published. Furthermore many of the basic principles relating to speech, language and dysphagia intervention can be generalised and applied to almost any communication or swallowing disorder. Speech-language pathology related to the management of MND is therefore not as illusive as some therapists might think, and if one took the time to broaden one's knowledge and become informed about new theoretical advances in the field, they may realise that this communicatively impaired sub-population is indeed worthy of intervention. However if speech-language pathologists are to broaden their knowledge and attain competency, as well as expect HCPs to accept them within the referral network, then researchers and clinicians need to engage in more rigorous research related to the communication and swallowing of persons with MND, as well as ensure wide-spread dissemination of study findings amongst the relevant professionals.

In reflecting upon the examples presented in this section of the discussion, it is clear that some of the issues which arose are minimally challenging or controversial when considering the spectrum of ethical problems that could confront HCPs. It would therefore seem that at some of the most basic levels of professional behaviour, clinicians are perhaps falling short. Not only do HCPs appear vague in terms of their professional commitment towards their patients, but also clinical practice that combines science and common sense, and is self-evaluated on a regular basis, appears questionable. In addition if HCPs are to ensure improved management for persons with MND, then these individuals need to embrace the role of patient advocacy in earnest. More so active advocacy on behalf of both patients and the profession is of particular importance in the field of speech-language pathology, especially if the

discipline is to dispel possible perceptions regarding futility and survive the competition that exists for limited healthcare resources (Hallowell & Chapey, 2001).

#### **4.1.5.4 A New Ethical Perspective**

The biomedical principles used for judging the rightness or wrongness of medical behaviours function as a standardised and accepted set of guidelines in traditional medicine. However because the underlying philosophies of traditional and alternative medicine differ from one another, the use of bioethical principles for guiding ethical practice in complementary and alternative medicine is not necessarily appropriate (Kubsch et al., 2005). Unlike traditional medicine which is based on Cartesian philosophy whereby the mind and body are viewed separately (Watson, 1988 as cited in Kubsch et al., 2005), alternative medicine adopts a holistic focus and promotes integrated wholeness within an individual (Kubsch et al., 2005). Furthermore because conventional bioethics is associated with the Hippocratic era, practitioners of traditional medicine especially physicians, are required to practise according to the Hippocratic oath which states, *“I will follow that system or regimen which, according to my ability and judgement I consider for the benefit of my patients”* (BMA, 1984 as cited in Gillon, 1985:68). With respect to this oath however, no mention is made of acknowledging patients’ opinions and following the course of action that they wish to pursue (Gillon, 1985). Such a declaration is therefore in contrast to the findings of the present study which revealed that participants wish to engage in their own healthcare and express their personal preferences. Unlike the Hippocratic perspective, alternative medicine focuses on treating the person and not the disease, and comprises a large subjective component such that professional behaviours are usually determined on the basis of patient preferences (Kubsch et al., 2005). Moreover because the approach of alternative medicine is care and not cure as in the case of traditional medicine (Kubsch et al., 2005), and for the time being a cure does not exist for the treatment of MND (Traynor et al., 2003), it seems apt that traditional HCPs involved in the management of this disease shift their focus and place greater emphasis on providing quality care for this patient population. The ethical practice of MND management might thus be improved if conventional HCPs consider the bioethical principles of traditional medicine in relation to those of holistic ethical practice, thereby giving rise to a more integrated and comprehensive perspective upon which to base MND healthcare service delivery.



In a study conducted by Kubsch et al. (2005), nurses involved in complementary and alternative medicine were asked to propose a set of ethical principles more appropriate for use than traditional bioethics. As a result, a set of six holistic ethical principles were proposed and validated for ethical infractions relating to the use of complementary and alternative interventions. For example practitioners of holistic medicine suggested firstly that the safety of different interventions be ensured, and that all false claims regarding efficacy of intervention be identified. Secondly it was proposed that professionals should be aware of their scope of practice, and only engage in clinical work for which they have received the appropriate training and possess a sufficient learned body of knowledge. It was suggested thirdly that interventions which are implemented also address the cultural diversity of patients, regardless of whether or not they are congruent with the practitioner's personal beliefs and value system. With regard to service delivery, it was recommended that all members of the public have access to the various interventions available, irrespective of their ability to meet the associated costs. The fifth holistic principle documented by Kubsch et al. (2005) was that of collaboration, specifically between the healthcare consumer and the alternative HCP so as to empower the patient and facilitate him/her in the healing process. Moreover because of the disproportion of power that exists between medical professionals and professionals of complementary and alternative medicine, Kubsch et al. (2005) also highlight the importance of collaboration between these two groups of practitioners, with the view of integrating conventional and alternative medicine. The final holistic ethical principle suggested was that of spirituality, where the spiritual philosophy of each intervention should not only emphasise quality of life and empower healthcare consumers to participate in their own life, but also respect simultaneously the spiritual diversity that exists between patients (Kubsch et al., 2005).

With respect to the aforementioned holistic ethical principles, it is evident that many of the suggestions raised by alternative practitioners have in fact been discussed in this study as potential solutions to some of the healthcare service delivery challenges that were established. For example as discussed under the various themes, greater collaboration between all members of the MND Unit has been proposed in response to the inequalities of the patient-professional relationship, while HCPs are urged to engage in efficacious interventions and ensure competency in their clinical approach.

More importantly, if one considers the holistic ethical principles of complementary and alternative medicine in relation to traditional medicine's patient-centred care, it is clear that similarities also exist between these two healthcare approaches. Accordingly in line with holistic ethics and the fact that HCPs should empower patients to engage in their own healing process (Kubsch et al., 2005), Mead and Bower's (2000) patient-centred dimension of "patient-as-a-person" requires the individual's experience of illness so that intervention can be tailored to suit his/her unique context. Furthermore the suggestion raised by Kubsch et al. (2005) for collaboration between the patient and the alternative practitioner, echoes the dimensions of "sharing power and responsibility" and "therapeutic alliance" or the need for an egalitarian patient-professional relationship in traditional healthcare (Mead & Bower, 2000). Since a common thread thus appears to run through both tenets of traditional medicine and the principles of holistic ethics, as well as the fact that many of the participants in this study reported the need for improvements in areas such as collaborative healthcare, acknowledgement of patient preferences, and enhanced HCP competency, the argument for integrating the doctrines and practice of conventional medicine with those of alternative medicine are therefore strengthened. More so, in combining differences such as scientific precision and spirituality inherent to both traditional and alternative medicine respectively, a more comprehensive ethical perspective for MND management may be realised, which might allow for every facet of a patient's being to receive healthcare that is all-inclusive and of the highest standards of integrity.

A further component of traditional bioethics that could be integrated into a new ethical perspective for the management of MND is that of virtue ethics. Rather than focusing on the moral act, virtue ethics concentrates on the moral agent and the character traits of individuals, the feelings of duty and responsibility under which one should work, and the role of conscience and intuitive responses to various circumstances (Boyd, 2005; Sim, 1997). In asking oneself the question, "*If I were to do such and such now, would I be acting justly or unjustly, kindly or unkindly [and so on]*" (Boyd, 2005:483), moral conflicts can be settled by determining which course of action exemplifies the more desirable moral character (Sim, 1997). The use of virtue ethics is therefore beneficial in solving various ethical problems (Boyd, 2005), although the approach has been criticised because virtuous principles do not inform

individuals how to respond to situations. Furthermore a mere focus on virtues and character traits to the exclusion of rigorous analysis of specific actions, may lead to a superficial assumption that all that matters in healthcare is to be the “right” person (Sim, 1997). However in view of the fact that the professional behaviours of some HCPs in this study were questioned, and instances arose where participants perceived some professionals to be uncaring and insensitive, it is possible that the management of MND might benefit from practitioners who place greater effort on trying to be the “right” person (Boyd, 2005) and who avoid vices such as, *“If I were to do such and such now, would I be acting in a way that is irresponsible, incautious, pusillanimous and short-sighted?”* (Boyd, 2005:483).

In relation to virtue ethics, a new ethical perspective for MND management may also comprise aspects of deontology. Given that quality of life should be the primary goal of MND management (Simmons, Bremer, Robbins, Walsh & Fischer, 2000), and the subjective nature of quality of life does not allow HCPs to determine this for their patients (Sullivan, 2003), by acting in accordance with one’s professional duties and refraining from treating healthcare consumers as a mere means to an end rather than as an end in themselves (Schüklenk, 2001), interactions with patients may allow them to experience brief yet repeated improvements in their quality of life. Finally, genuine communication between the person with MND and the HCP may also be a valuable contribution towards a new ethical perspective. According to Boyd (2005), a hermeneutic approach associated with bioethics claims that when individuals with different perspectives on a subject engage in conversation and listen and talk to each other, the net result may be a new shared perspective that is more satisfactory to each person than their initial perspective. Hence if HCPs involved in the management of MND learn how to better communicate with persons with the disease and their family members, then they may be able to reach common ground in terms of solving various ethical problems in a way that is both acceptable to healthcare consumers and congruent with ethical practice.

In view of the fact that traditional bioethics appears to focus on the rightness or wrongness of medical professional behaviours, while holistic ethics concentrates more on caring for the healthcare consumer, a combination of the differences and similarities of these two approaches to create a new ethical perspective may offer

persons with MND and their families the best opportunity for receiving ethically sound service delivery. Moreover from a bioethical perspective, it is evident that comprehensive ethical practice possibly needs to extend beyond the use of principle-based bioethics alone, to include other approaches that not only consider the moral action but also the moral agent. Notably however, a marriage of traditional bioethics with that of holistic ethics in order to establish a new ethical perspective upon which to base MND healthcare service delivery, must first undergo rigorous research and be validated for ethical infractions relating to the management of this patient population.

## **4.2 IMPLICATIONS OF CONTEXTUAL VARIABLES**

Now more than ever before the context in which HCPs work has a significant influence on the delivery of healthcare services. Global changes in healthcare policies, reimbursement schemes, political climates, and professional training have had and continue to have a dramatic impact on access to healthcare and the quality of services that professionals provide (Hallowell & Chapey, 2001). By investigating service delivery through exploring the perceptions of healthcare consumers regarding the medical and rehabilitative management of MND, this discussion has highlighted areas in need of improvement or change to be adopted by HCPs and support organisations in pursuit of improved quality of healthcare. However because participant perceptions alone appear impractical for achieving optimal management, the findings of the present study need to be viewed against the current healthcare context in an attempt to achieve high quality healthcare for persons with MND. Consideration in terms of healthcare service delivery reform, societal awareness, and professional well-being may therefore aid in helping the recommendations documented in this discussion become a reality.

### **4.2.1 Healthcare Service Delivery Reform: A New Model**

The South African healthcare system has borne the grunt of many changes in the country. It has been affected by increasing urbanisation, unemployment and social instability, as well as a decline in the economy, a depreciating Rand, and rising costs of inflation. Moreover because South Africa is committed to providing healthcare to all, resources have been made available for early preventative care and the promotion of health (i.e. primary healthcare), as opposed to more expensive curative medicine (Gilbert & Gilbert, 2004). Healthcare in South Africa has thus had to undergo major

structural and financial reform, and HCPs have been challenged to adapt to a changing system (Arnetz, 2001; Gilbert & Gilbert, 2004).

In response to the escalating costs of healthcare, changes in service delivery around the world have occurred mainly in the form of managed care frameworks (Pietranton, 1998). Although the three main goals of managed care include quality and coordination of healthcare, access to care for persons who need it, and cost control (Henri & Hallowell, 1999 as cited in Hallowell & Chapey, 2001), some researchers believe that this healthcare framework has complicated service delivery and access for persons with chronic and disabling conditions, as well as prevented meaningful improvements in the delivery of services for these individuals (Beatty, Hagglund, Neri, Dhont, Clark & Hilton, 2003). Similarly as revealed in the present study, persons with MND did not have access to all healthcare services that they required. In some instances not only was financial support problematic, but also the quality of care rendered was perceived by the majority of participants to be poor and unsatisfactory. Moreover in response to these obstacles, this study has demonstrated that not only does the management of MND fail to impose a business incentive which might facilitate the establishment of accessible, comprehensive, and high-standard healthcare, but also in terms of competition for limited resources it is unlikely that this condition features high on the list of priority diseases. Unlike the global phenomenon of HIV/AIDS for example, where its dramatic spread across Southern Africa is threatening society (Gilbert & Gilbert, 2004), MND is more contained and does not threaten communities by and large. Because MND does not therefore appear to be one of the “glamorous” conditions that prompts a lucrative enterprise, and multinational pharmaceutical companies are more likely to devote their research and development budgets to the furthering of “hot topics” such as malaria, tuberculosis and HIV/AIDS for example (Gilbert & Gilbert, 2004), the resulting logistical support and financial backing for MND management is seemingly inadequate. The onus thus appears to rest with HCPs committed to the management of persons with MND, to address the challenges and inequalities faced by this clinical population and advocate for change.

In acknowledging the challenges related to management and the need for healthcare service delivery reform, implications are therefore evident in terms of developing a

new and innovative service delivery model that is best suited for MND healthcare consumers and HCPs, in pursuit of high quality healthcare. Moreover in developing such a model, international standards of care may provide South African HCPs with a starting point from which to work. However given that this study has demonstrated that global trends alone are likely to be inadequate for guiding MND management in South Africa, local HCPs are thus urged to look towards the current healthcare setting in order to create unique and context-specific clinical policies, protocols and pathways. For example, more comprehensive yet cost effective healthcare for persons with MND in the South African context might be achieved through a transdisciplinary model of intervention rather than a multidisciplinary approach. Included in a new model of service delivery, quality and cost-effective management of MND in the South African healthcare setting may also be improved by the introduction of community-based rehabilitation for example. In other words management would strive to ensure rehabilitation for all MND healthcare consumers and achieve equalisation of patient opportunities, whilst simultaneously encouraging social integration of such individuals. Furthermore by involving individuals, their families, and the community in a new model of service delivery, as well as incorporating the provision of appropriate health, education, vocational and social services, in the context of MND management, quality healthcare and self-sustainable improvement in the well-being of persons with MND and their families may also be achieved (SASLHA, n.d. c).

Another means of innovative service delivery for the benefit of HCPs includes the development of entrepreneurial skills. In the case of speech-language pathology for example, regardless of whether HCPs work in hospitals, rehabilitation centres, or private practice, they can no longer assume a steady flow of patients at the door (Hallowell & Chapey, 2001; Pietranton, 1998). As a result HCPs need to identify professional opportunities and become entrepreneurs by demonstrating their clinical skills, promoting cost-effectiveness, and creating a demand for their services (Pietranton, 1998). HCPs thus need to engage in marketing strategies, whereby they define what a patient needs, produce the relevant service, and let others know about this service that is “for sale” (Matthews, 1988 as cited in Hallowell & Chapey, 2001). Hence in the case of MND, all HCPs involved in this area of practice need to establish the specific needs of their healthcare consumers. Perhaps by engaging in more

patient-centred research and eliciting more discipline-specific information, the perceptions of participants may inform HCPs further with regard to particular healthcare needs. Thereafter more comprehensive MND management programmes can be developed that not only meet the needs of South African healthcare consumers, but are also in line with standards of best practice and demonstrate a sensitivity towards efficacious intervention.

In view of the team approach to MND management, all HCPs also need to engage in collaborative marketing such that each team member is involved in developing and disseminating educational materials (e.g. brochures, educational pamphlets and newsletters), as well as meeting and educating other HCPs or referral agents (e.g. support organisations) and creating healthy relations with case managers and reviewers who make rules and reimbursement decisions regarding Medical Aids and managed care (Hallowell & Chapey, 2001). The role of entrepreneur and marketer is therefore essential for all HCPs if they are to protect the well-being of healthcare consumers and enhance the management of MND, as well as dispel the idea that both the public and professionals may have in terms of MND being a disease for which nothing can be done. More so by involving themselves in public relations, HCPs are placed in a position whereby they can maximise their own career opportunities, secure their financial stability, and safeguard their clinical autonomy (Pietranton, 1998). In implementing such creative and innovative strategies to establish a more context-specific and discipline-specific model of service delivery, the potential therefore exists for current management practice of persons with MND to be reformed and substituted by what healthcare consumers might perceive to be more acceptable.

#### **4.2.2 Societal Awareness**

The perceptions of participants from this study suggest that amongst some members of the healthcare community there appears to be a certain level of ignorance with regard to MND. For example, the speech-language pathologist who stated that nothing could be done for the person with MND perhaps did so based on a paucity of knowledge regarding the disease. Such ignorance may be related to Conradi's (1999) belief that research and knowledge pertaining to MND lags behind that of other diseases. Furthermore despite treatment approaches having been developed for the management of MND (Ludolph & Riepe, 1999), scepticism about intervention still

appears to exist, along with a general attitude that without a cure there is no value in pursuing patient-specific approaches. In relation to the fact that one of the most traumatic experiences for patients with cancer is to be given the impression by the oncologist that nothing can be done (Baider & Wein, 2001), the current study demonstrates that the attitudes of nihilism portrayed by certain HCPs has the potential to affect healthcare consumers negatively and destroy their hope. Since the societal attitudes of HCPs and even healthcare consumers thus function as a further contextual variable that has the capacity to impact either positively or negatively on the management of MND, efforts to educate both professionals and the public about this disease should perhaps be considered.

By adopting the role of educator, MND HCPs are provided with powerful opportunities to engage in health professional education so as to educate all members of the healthcare team. According to Coles (1995) healthcare education should begin with students, expand when staff is newly qualified, extend into specialist education, and be included in continuing professional development. Such comprehensive health professional education might aid in dispelling pre-existing and potential nihilistic attitudes regarding MND, as well as advocate for optimal medical and rehabilitative management of this patient population. In addition by addressing managers of healthcare services at a national level with respect to healthcare funding and the drafting of healthcare policies for example, education may assist in shifting a mindset in order to achieve equilibrium between financial concerns and patient-centred care (Coles, 1995). By further engaging in in-service training for administrators, formal caregivers, and other professionals working within the healthcare arena (Hallowell & Chapey, 2001), knowledge regarding MND may also become more widespread, as well as the appropriate means of achieving high-quality healthcare for this disease. In essence therefore, it is through these educational efforts and involvement in continuing professional development, that HCPs may experience an increase in their knowledge and understanding, feel less overwhelmed and more supported to adopt a role in the management of MND, and thus become an advocate for high quality healthcare.

Given the apparent ignorance of HCPs regarding MND, it is perhaps understandable why members of the public might also lack knowledge of this condition. Reportedly



in the case of Units 2 and 6, following diagnosis family and friends distanced themselves from the person with MND, and participants believed that this was because these individuals associated severe physical disability with cognitive decline. As a result, the need arises to educate members of the public about this devastating condition in the hope that these individuals will then function as an additional support for persons with MND and their families. By collectively empowering individuals in the community through the provision of information (Hallowell & Chapey, 2001), the public may be stimulated into experiencing self-control, mastery, and power to effect change in the lives of persons with MND and help them to feel valued in society. Knowledge and understanding of disability by individuals other than the patient's HCPs is therefore essential, because without this foundation persons with MND face negative consequences in the form of declining mental health and reduced social participation (Beatty et al., 2003). Consequently the recommendation for a social model of intervention, coupled with the acknowledgement of systems theory and the implementation of community-based rehabilitation, provides a suitable platform to educate and achieve greater societal awareness. Such awareness would in turn enhance the well-being of persons with MND and their families, promote membership in a communicating society, and ultimately improve the perceptions of healthcare consumers regarding the medical and rehabilitative management of persons with MND.

In an attempt to further achieve public awareness and a change in societal attitudes, HCPs possibly need to consider promoting MND by raising it to a celebrity status. As in the case of paraplegia, Christopher Reeves otherwise known as "Superman", drew on his fame as an actor to secure funds for the development of the Christopher Reeves Foundation. Not only did his celebrity status raise public awareness about spinal cord injury, but it also encouraged the raising of funds for his foundation which aids in caring for individuals with impaired mobility and providing research grants. Similarly advocates of MND may also wish to go in search of celebrities, sports stars, or any other individuals who would be prepared to use their personal story in an attempt to raise public awareness and financial support for the benefit of persons infected and affected by this catastrophic disease. Whilst Steven Hawking is more well-known for his ingeniousness than his diagnosis of ALS, his celebrity status does not imply automatically that he is responsible for becoming the sole custodian of

MND care. However it is possible that if advocates of the disease approached him, efforts could be made to use his story as a platform for others to learn about the condition and for funding strategies to be initiated. In addition by virtue of the fact that Steven Hawking has been living a successful life with ALS for many years, his story may serve to offer persons with MND and their families a sense of hope and opportunity to perceive the disease as more than just a death sentence.

In relation to the need for innovative models of service delivery, a further means of achieving public awareness and gaining financial support is for HCPs in South Africa to consider engaging in fundraising events. With the decrease in revenues associated with clinical services, many HCPs involve themselves in supporting fundraising efforts. Specifically such efforts usually include collaboration in the development of fundraising materials, establishing and expanding donor clients, meeting existing and potential donor clients, as well as establishing partnerships with various organisations (Hallowell & Chapey, 2001). In view of the enormous costs relating to chronic healthcare (Coles, 1995), HCPs might therefore consider engaging in rigorous fundraising efforts to address the financial concerns surrounding the management of MND. Although fundraising initially may need to start on a small scale by drawing on public awareness and targeting generous individuals, as advocacy improves and HCPs begin demonstrating outcomes for the services that they render, larger corporations and foundations could perhaps be approached. Thus by promoting public awareness through advocacy, education and fundraising, ignorance regarding MND may be reduced such that the stage is set for healthcare consumers to experience more positive healthcare.

#### **4.2.3 Professional Well-Being**

HCPs who dedicate their lives to sharing their knowledge, caring during the process of death and dying, and exuding a supportive self-assurance to patients, often long to escape the overwhelming vulnerability and empathy that they feel. Considering therefore the well-being of HCPs is evidently an important issue in healthcare, in addition to the fact that the psychological distress of clinical practice can result in professionals devaluing the views of their patients, failing to attend to patient perceptions, and omitting patient information, practitioners are also likely to experience reduced coping, anxiety and insecurity (Baider & Wein, 2001). The third

and final contextual variable that thus appeared to have an impact on the management of MND was that of the well-being of HCPs. Whilst recommendations for improving the quality of MND healthcare have been presented throughout this discussion, it seems logical that many of these suggestions will only be achieved if the well-being of HCPs is safeguarded.

The fact that few HCPs appear dedicated to work in the area of MND, and others have suggested that professionals should not waste their skills working with degenerative conditions, perhaps implies an underlying fear on the part of these individuals to engage with patients who are severely disabled. These fears are possibly a vehicle for avoiding the stress that is associated with emotionally-intense patient-professional relationships, and situations that force HCPs to confront death (Isikhan, Comez & Danis, 2004). In addition, the fact that participants in this study perceived HCPs to be inadequate and unprofessional may further be a consequence of working with chronically ill patients. HCPs who are involved in the management of persons with terminal illness are at risk for experiencing considerable stress, such that a high incidence of tension, anxiety, cynicism, decreased job satisfaction, and even burnout exists amongst these professionals (Dunning, 2005; Isikhan et al., 2004). Participants in the present study may have therefore mistaken the natural reactions of professionals to stressful circumstances as seemingly unprofessional and inadequate care. Arnetz (2001) thus states that although the patient-professional relationship is at the core of the healthcare encounter and the source for gratifying healthcare experiences, it also poses a significant emotional risk for HCPs. It is therefore mandatory that HCPs accept that death and dying is an intrinsic part of the profession, and develop advanced coping strategies to allow them to function at an optimal emotional and intellectual level in the presence of various associated stressors. Hence implications are apparent with regard to future research, and the fact that if specific stressors inherent to HCPs and their practice could be better understood, then the likelihood exists that the kind of support that these individuals need in such stressful patient-professional relationships could be determined (Isikhan et al., 2004). In other words by employing efforts to improve and safeguard the well-being of HCPs, the quality of healthcare provided to persons with MND may also be enhanced, because when professionals are able to recognise, question, accept, and reflect upon their emotional

wounds, they learn how to integrate their experiences into the healing relationship and transcend the boundaries of quality healthcare (Dunning, 2005).

In conclusion it is thus evident that in view of the current healthcare climate, there are a variety of contextual variables that have the potential to impair optimal MND management. However by taking these variables into consideration and utilising them in innovative and creative ways to develop a new model or framework of service delivery, healthcare service delivery reform could in fact benefit the well-being of both MND healthcare consumers and MND HCPs.

### **4.3 PROPOSED NEW FRAMEWORK OF IDEAL SERVICE DELIVERY FOR ALL PERSONS IMPLICATED IN THE MANAGEMENT OF MND**

#### **4.3.1 Integrative Discussion**

With respect to the findings of the present study, the perceptions of persons with MND and their family members regarding medical and rehabilitative management arose from experiences which were categorised into five domains and included health communication, the interventions that were rendered, support systems in-situ, involvement in complementary and alternative medicine, and the bioethical practice of HCPs. However many of these experiences overlapped one another in terms of the domains into which they were placed, and thus while for ease of reporting the discussion that was provided may seem simplistic in the sense that the five major themes were discussed in isolation, there are in fact no precise boundaries differentiating each of these areas. For example, the lack of shared decision-making reported by participants may have arisen from the fact that HCPs reportedly failed to provide sufficient information for persons with MND to make choices about their future. And poor informational exchange may have been a consequence of poor communication between persons with MND and their HCPs, especially in the presence of the communication impairment and the fact that practitioners appeared to experience difficulties when confronted by their communicatively impaired patients. Thus poor exchange of information between the person with MND and the HCP, coupled with the inability to achieve successful communication between one another, is likely to have resulted in the professional being ineffective in upholding the principles of bioethical practice. Consequently participants might have experienced their autonomy being over-ruled, as well as principles such as beneficence and

veracity being undermined. In addition because of a paucity of information and a general disregard for their rights to healthcare, participants reported a lack of support from HCPs. Moreover this lack of support was reinforced by the fact that follow-up appointments were non-existent, and thus there were no opportunities for repeated information exposure or referral to receive a variety of interventions from different HCPs. In the presence of a lack of support and general dissatisfaction for the management of MND, participants appeared to find comfort, an improved sense of well-being, hope, and general satisfaction in pursuing complementary and alternative medicine. In essence therefore it is evident that all five domains discussed in this study are interconnected, and it is thus understandable that a breakdown in one area is likely to have disrupted the other domains and hence impaired the perceptions of healthcare consumers regarding the overall quality of MND management.

Further to the interconnected experiences of participants regarding their healthcare, it is clear that the perceptions of MND management are also influenced by South Africa's current healthcare climate. Because service delivery in the country has had to undergo reform in an attempt to manage escalating healthcare costs and ensure a more equal distribution of services and resources, the management of MND is characterised by various loopholes. For example rather than involvement with multiple professionals and multiple approaches necessary for complementing an inclusive management programme, current MND management services appear scant and fragmented. Moreover because the status of MND does not rank it amongst the high priority diseases that attract both local and international, and public and professional attention, it lacks the financial support necessary for devising high quality comprehensive management programmes. Also the emotional nature of MND places a significant burden upon HCPs who are involved in this area of practice, and thus the quality of care that is rendered by such professionals has the potential to be affected by their own well-being. Consequently both contextual variables and variables inherent to management services which impinge upon the medical and rehabilitative management of MND, ultimately influence the perceptions of healthcare consumers regarding the quality of care that they receive.

#### **4.3.2 Ideal Service Delivery for Healthcare Consumers of MND Management**

In response to the preceding discussion and the implications that have been documented throughout this study, the need for a disease-specific and context-specific management framework is evident. Figure 6 therefore presents a proposed new framework of ideal service delivery for healthcare consumers of MND management. The aim of this framework is to facilitate HCPs in providing a more comprehensive approach to the management of this disease. Moreover the basis of the framework originates from the principles of a social model, whereby the perceptions of MND healthcare consumers regarding management arise not only from the interventions or treatments that are received as a direct consequence of the disease, but also from the relationships that are established between the patient and professional, factors intrinsic and extrinsic to both of these parties, as well as environmental and contextual variables. As a result, HCPs are therefore required to make a philosophical shift from a medical model of practice towards a more social approach. By focusing on a variety of internal and external variables that have the potential to influence the management of MND, healthcare extends beyond addressing MND per sé (i.e. the physiological sequelae of the disease), and also addresses the broader context in which one lives with the disease, as well as the affected individual's lifestyle and associated psychosocial well-being.

Given that patients' experiences are a fundamental source for evaluating the quality of care that is provided by HCPs (Berwick, 2002 as cited in Arora, 2003), at the centre of the proposed new framework of ideal MND service delivery lies the perceptions of persons with MND and their family members regarding the quality of management that is received. Arising from the five themes discussed in this study, the perceptions central to this framework include a) patient-centred communication, b) patient-centred care, c) support networks, d) complementary and alternative medicine, and e) bioethics. Each of these five areas of practice have been established as significant domains required for high quality MND management, because not only do they have the potential to have a direct influence on the perceptions of the healthcare consumer, but also the influence that they have on each other further impinges on the overall management process. Hence by modifying one area of practice, the other domains are also likely to be affected. The key to achieving optimal quality in healthcare therefore appears to lie in improving practice in all five areas, because it is then that a state of

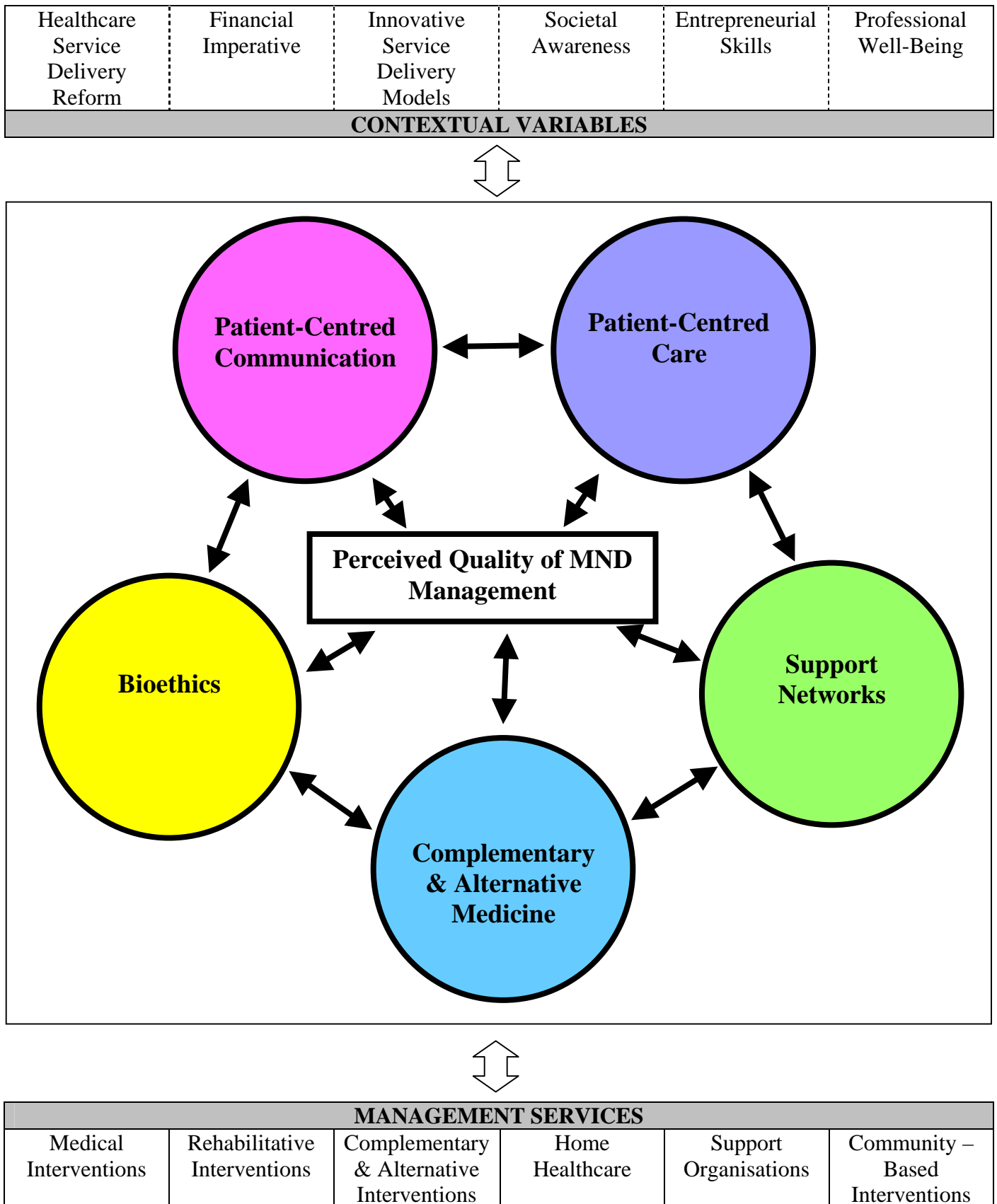
equilibrium is likely to be attained, and the perceptions of healthcare consumers regarding the management of MND are likely to be at their greatest in terms of satisfaction.

Inherent to a social model, because disability is not a consequence of the impairment alone but also a result of the attitudes and barriers imposed by society (Simmons-Mackie, 2001), in the case of MND the perceptions of healthcare consumers regarding the quality of management are also likely to be affected by the socio-political context in which a healthcare framework is implemented. In other words, the financial status of the current healthcare climate and the demands for service delivery reform for example, further contribute to the perceived quality of MND management. The second component of the proposed new framework of ideal MND service delivery, therefore includes a variety of contextual factors that are likely to influence and be influenced by the perceptions of healthcare consumers. This framework is evidently a fluid system, with multidirectional influence between the different contextual variables and perceptions relating to MND service delivery. With respect to this multidirectional influence and the current socio-political climate however, implications arise in the sense that rather than waiting for “somebody else” to instigate change in a seemingly compromised system, MND HCPs need to embrace both the positive and negative ramifications of contextual variables on the quality of services that they render, and begin developing innovative ways of transforming the negative factors into more desirable experiences. Hence by developing entrepreneurial skills, encouraging societal awareness, and safeguarding one’s own well-being for example, HCPs create an opportunity to achieve more acceptable health outcomes and ultimately more positive perceptions of MND management.

Lastly in developing a proposed new framework of ideal service delivery, one needs to acknowledge that MND is a life long feature of those infected and affected by the disease. As individuals learn to live with the condition and their life situations change as the disease progresses, so too do their needs for different types of management services. During such long-term conditions, patients and their families should thus have access to a variety of HCPs and support organisations that can provide holistic management (Simmons-Mackie, 2001). In the case of MND it is clear that quality management needs to extend beyond medical and rehabilitative interventions, and

even beyond complementary and alternative medicine, and also include more practical services that function to ease the physical and emotional burden for both the person with MND and his/her family. Such practical amenities might include home healthcare and support organisations for example. An expanded service delivery framework is therefore vital to the treatment of a progressive condition, so as to account for the long-term consequences of the disease and provide the patient and family with an integrative management programme to address holistically every need of the Unit. The third component of the proposed new framework of ideal MND service delivery, thus includes a comprehensive array of management services that aim to assist both the person with MND and his/her family, bearing in mind that the experience of MND amounts to more than the physical ramifications alone.





**Figure 6: Proposed New Framework of Ideal Service Delivery for Healthcare Consumers of MND Management**

## CHAPTER FIVE

### CONCLUSIONS AND IMPLICATIONS OF THE STUDY

#### 5.1 SYNOPSIS OF THE STUDY

The aim of the present study was to investigate the perceptions of persons with MND and the perceptions of their family members with regard to the medical and rehabilitative management received on and following diagnosis. An awareness of the perceived nature of MND management was deemed necessary given that a treatment does not exist currently to cure or halt disease progression, and HCPs are therefore obliged to understand the requirements of their patients and the family as they journey with them from health to disability, and attempt to provide the highest standards of care, compassion, and an integration of healthcare services (Francis et al., 1999; Leigh et al., 2003). Moreover with respect to the fact that persons with MND often present with relatively intact cognition (Francis et al., 1999), and they are likely to have their own opinions regarding the healthcare that they receive, the communication impairment inherent to many with this disease has perhaps previously excluded this patient population from opportunities to convey their perceptions pertaining to MND service delivery. To this end the sub-aim of this study set about exploring the perceptions of persons with MND and the perceptions of their family members with regard to the role that the communication impairment may have had on the healthcare that was received. After all effective health communication is the prime “currency” used by patients to put forth their healthcare perspectives (Schapira, 2003).

Whilst perceptual measures are reportedly the fundamental source for evaluating the quality of healthcare services rendered (Arora, 2003), to the researcher’s knowledge patient perceptions regarding MND management have not been documented explicitly in the literature. The present study therefore investigated medical and rehabilitative MND service delivery by interviewing individuals both infected and affected by this disease so as to elicit their perceptions regarding management. Face-to-face interviews were conducted in accordance with an interview schedule entitled, “The Communication Taxonomy of Perceptions Regarding the Medical and Rehabilitative Management of Motor Neuron Disease”. This interview schedule was developed by the researcher in response to parameters of typical human communication, as well as pilot reports of what healthcare consumers with long-term health conditions perceived to constitute acceptable healthcare and acceptable health communication.

Furthermore with the aim of understanding MND management from the perspective of the communication impairment, it was mandatory that study participants presented with communicative difficulties. The Frenchay Dysarthria Assessment (FDA) (Enderby, 1984) was therefore used to assess formally the motor speech abilities of each person with MND, as well as quantifiably ensure the presence of a communication impairment.

The foundation of the present study was embedded within the tenets of three overlapping theoretical frameworks. The cornerstone of quality healthcare in the form of *patient-centred care* (Schulman-Green, Naik, Bradley, McCorkle, & Bogardus, 2006), offered the researcher the possibility of investigating MND management from not only a medical perspective, but also from the patient's perspective in terms of considering factors such as his/her psychosocial context and the presence of an egalitarian patient-professional relationship characterised by unconditional positive regard (Mead & Bower, 2000). Since the attainment of these patient-centred ideals are however dependent upon sound health communication (Ammentorp et al., 2007), the concept of *patient-centred communication* as a central component to quality clinical service delivery was also included in this study (Epstein et al., 2005). In addition a *bioethical approach* to practice was adopted, in view of the fact that if HCPs want their patients to achieve positive health outcomes and experience high standards of care that is patient-centred, then amongst other factors healthcare consumers need to be given a sense of autonomy, perceive the health professional as loyal and beneficent, and perceive the entire healthcare experience as morally acceptable (Epstein et al., 2005; Strand, 2003; Strand et al., 1998). Thus by aiming to achieve sound bioethical practice for example, healthcare that is concordant with the ideals of both patient-centred care and patient-centred communication is also likely to be achieved, thereby contributing ultimately to more positive healthcare consumer perceptions regarding the quality of MND management.

Notably while the aim of this study was not to provide solutions to the healthcare inadequacies raised by participants, as a consequence of investigating healthcare consumer perceptions implications were inevitable for HCPs in general and speech-language pathologists alike, as well as for healthcare organisations and healthcare funders in pursuit of improving the quality of medical and rehabilitative MND

management. However to determine the feasibility of these implications, such recommendations were considered in accordance with current healthcare requirements for managed care and evidence-based medicine, against global trends in MND service delivery that interact with the pressures and realities of South Africa's current healthcare system (Gilbert & Gilbert, 2004). Finally in an attempt to apply the findings of the present study to a broader context, as well as attain a comprehensive yet feasible management regime, a framework of ideal service delivery for healthcare consumers of MND management was proposed.

## **5.2 SUMMARY AND CONCLUSIONS OF THE MAIN FINDINGS OF THE STUDY**

The overarching finding of this study revealed that apart from those participants who consulted complementary and alternative professionals, professionals abroad, or certain professionals with experience in the field of MND, persons with this disease and their family members perceived current medical and rehabilitative management to be unsatisfactory. Despite variations among Units and a consideration for individual variability, participants indicated that HCPs generally demonstrated a poor attitude towards the management of MND. Moreover although international literature asserts that MND must be viewed as a treatable condition (Gelinas, 1999a), the general perception in this study was that because death is an inevitable consequence of the disease, HCPs do not see the value of pursuing different management options devoid of a cure. Not only were participants thus denied their right to comprehensive healthcare and a rightful opportunity to engage actively in their own healthcare, but they also felt unsupported, abandoned and misinformed, thereby having to make the MND journey on their own. As a result the findings of this study in terms of defective health communication, intervention, support systems and bioethics, as well as the desire for complementary and alternative medicine, suggest that current medical and rehabilitative management of MND in the South African context is not characterised by patient-centred communication, patient-centred care, or sound bioethical practice.

With regard to findings of ineffective patient-centred communication, a two-fold origin was found to exist. Firstly perceptions of poor health communication appeared to stem from the fact that most medical and rehabilitative HCPs were perceived to be

poor communicators. While excessive use of jargon and complex sentences on the part of HCPs reportedly impaired participants' understanding during healthcare encounters for example, a paucity of information provided by professionals about the disease was perceived to hinder persons with MND and their family members from making important decisions about the future. In addition the manner in which information was delivered to participants was perceived to be cold, blunt, and callous, thereby further contributing to the negative experiences reported with regard to MND management. Related to explanations of poor health communication stemming from HCPs being perceived as poor communicators, this finding also appeared to be exacerbated by the communication impairment and the fact that it appeared to hinder HCPs from offering persons with MND opportunities to ask questions during healthcare encounters. In addition the fact that these professionals were perceived to be unaware of whether or not a breakdown in patient understanding and/or patient-professional communicative transactions had occurred, suggests that more than just poor communicators HCPs are perhaps also unskilled or untrained, and possibly even fearful of engaging with individuals who are unable to communicate in the conventional manner.

Since the communicative behaviours of HCPs are not generated in isolation but rather in conjunction with those of healthcare consumers (Arora, 2003), the second factor which further compromised patient-centred communication in this study was the fact that persons with MND were also perceived to be poor communicators. Although the literature reports that some patients do demonstrate poor communication within the healthcare arena (Parrot, 1994; Street, 1991), the findings of this study appeared to be related directly to the communication impairment. In particular the communication impairment reportedly restricted spontaneous communicative transactions between persons with MND and HCPs, thereby limiting their own healthcare and disempowering them from engaging actively with all members of the Unit. As a result MND healthcare consumers reported taking a "backseat" in their own healthcare, as well as experiencing a sense of disempowerment to quality health communication and MND management in general.

Further to factors such as misinformation, a paucity of information, and a lack of communicative warmth compromising patient-professional interactions as a result of

limited professional skill and communication training (Ammentorp et al., 2007; Tran et al., 2004), the findings of the present study revealed that poor health communication in the context of a terminal illness extends beyond deficits in core health communication skills. For both persons infected and affected by MND, the physical and emotional devastation of the disease appears to activate intrinsic coping mechanisms that regulate the distress experienced by these individuals. In an attempt to alleviate and control such distress therefore, persons with MND and their family members may perceive any overwhelming experiences to be characterised by misinformation and a lack of responsiveness for example, in turn translating into perceptions of poor health communication. Moreover for HCPs, their ability to engage with patients according to parameters of acceptable patient-centred communication also appears to be affected by the burdensome nature of MND. The use of jargon and a cold manner of information delivery for example, may be a manifestation of HCPs' realisation that more than being unable to cure patients with MND, they are also forced to face their own emotions such as a fear of death and threats to their own mortality (Anstey, 1991). And thus while such health communication traits may be perceived as less than satisfactory for healthcare consumers, at the very least they appear to provide an outlet for alleviating the distress experienced by HCPs.

Despite the criticisms documented in modern literature that biomedical models of healthcare restrict patient care to the biological dimension of illness and disregard the patient's psychosocial context (Borrell-Carrió et al., 2004), findings of the present study revealed that ironically current medical and rehabilitative management of persons with MND does not even account in full for their biomedical needs. Integrated healthcare with consideration for the biopsychosocial factors of patients was clearly absent in this study. For example apart from few persons with MND having regular follow-up appointments with a neurologist post diagnosis, referrals for rehabilitation and support groups were scant. Moreover although a team approach for MND management reportedly offers patients the best chance of survival (Leigh et al., 2003), this type of intervention was also lacking in the present study. Participants consequently reported a lack of continuity in their care, as well as a general sense of abandonment. In addition because most HCPs were perceived to have a negative attitude towards MND management, commonly informing persons with MND that

nothing can be done for individuals with this disease, these professionals appeared to be practising from a paternalistic framework. On the basis of their epistemic authority (Ross & Deverell, 2004d), many HCPs may have consciously or unconsciously denied healthcare consumers information about their illness and access to different management services, thereby ultimately denying them the opportunity to engage actively in their own healthcare and participate in the decision-making process. As a result several participants in this study reported the medical and rehabilitative management of persons with MND to be feeble and inferior, devoid of the ideals that comprise patient-centred care.

Whilst a lack of comprehensive MND management and patient-centred care might at first glance suggest general disregard on the part of the healthcare fraternity for persons with MND, such a finding may also demonstrate more aptly clinical ignorance on the part of some HCPs. For example in the absence of a MND healthcare team, communication and collaboration between the relevant HCPs is limited, thus translating into a lack of networking opportunities and a lack of shared knowledge amongst professionals. As a result some HCPs who are unfamiliar with MND may be genuinely unaware of the management services that are available for persons with this disease. In addition the absence of patient-centred care and acceptable MND management in general, also appears to highlight the need for some HCPs to shift their mindset with regard to the management objectives of this disease. Rather than perceiving personal failure and “washing their hands” of persons with MND because no cure exists (Leigh et al., 2003), HCPs need to acknowledge that in this instance their fundamental role is one of educator, advisor and counsellor, functioning collaboratively in a team to maintain skills and promote quality of life for both persons with MND and their family members (Miller et al., 1997). Moreover such collaborative efforts may also function to reduce the burden of healthcare for some HCPs, thereby allowing them to perceive the management of MND in a more positive light, and in turn approach patients from a less paternalistic and more patient-centred perspective.

With regard to speech-language pathology services in particular, few persons with MND were receiving intervention at the time of this study. Apart from positive perceptions elicited by two individuals who were consulting speech-language

pathologists with experience in the field of MND, other participants either reported negative experiences after engaging in speech-language pathology consultations or did not receive this type of intervention at all. Further to these negative experiences revealing that some HCPs are possibly unfamiliar with the communication and swallowing difficulties common to persons with MND, the fact that participants in this study were not referred for speech-language pathology intervention suggests that the profession is also omitted from the referral network. Thus apart from professionals' reduced involvement in the management of MND possibly arising from a lack of willingness or drive to engage with patients who present with such an intense physically and emotionally disabling condition, this finding may also relate to the possibility that the profession has perhaps failed in proving itself sufficiently in order to secure a steady flow of speech-language pathology referrals. Within the realm of MND management therefore, the profession of speech-language pathology as a whole as well as individual speech-language pathologists, are evidently in possession of a weak clinical and professional identity that results in both healthcare consumers and HCPs holding this area of rehabilitative healthcare in the slightest regard.

Congruent with patient-centred care, individuals with a terminal illness require support in the form of information, care, and psychological assistance (Richardson, 2004). Likewise quality MND management also requires that the psychosocial well-being of the patient and family is addressed (Francis et al., 1999), although both persons with MND and their family members in this study perceived support systems to be inadequate. The fact that information about the disease and recommendations for a variety of management services were scarce, left participants feeling unsupported and abandoned. In addition while support organisations do exist for persons with MND, participants in this study perceived such services to be fragmented and inconsistent. Arguably however fragmented MND service delivery may in part be attributed to a lack of resources and the fact that providing accessible services to all healthcare consumers, especially when the disease in question is relatively rare, is an ongoing struggle for all South African healthcare providers and healthcare funders. More so by virtue of the findings of the present study, the value of a MND team is further highlighted. In the presence of greater inter-professional collaboration and control, HCPs might be in a better position to identify, develop, and provide management services and support structures that are constantly accessible to



persons with MND and their families, as well as secure the resources that are necessary for sustaining such supportive healthcare.

The negative attitude of some HCPs regarding MND management further compromised participants' perceptions relating to the support that they had received. In particular participants were dissatisfied with the fact that HCPs did not attempt to understand the individual's experience of living with MND, and thus consider the "patient-as-a-person". Also poor therapeutic alliance resulted in failure to achieve empathy, compassion, and unconditional positive regard for the purpose of enhancing the patient-professional relationship and the healthcare experience as a whole (Mead & Bower, 2000). Furthermore because many HCPs may have avoided meaningful interactions with patients in view of their lack of skill in communicating effectively with communicatively impaired individuals, and participants may have avoided engaging in exchanges where the potential for communicative breakdowns existed, opportunities for genuinely warm and supportive patient-professional relationships were further restricted. Moreover with regard to the involvement of family members in the management of MND, although their interactions with HCPs were perceived to be more acceptable and more natural because conventional communication could be utilised, these individuals nonetheless felt unsupported and abandoned in their own right. Such negative experiences were related primarily to the fact that not only are formal services unavailable to train family members to cope with the practicalities of caregiving, but also a lack of adequate support systems implies that such caregivers are not provided with the psychological assistance required to cope with the emotional demands of caring for a loved one (Jansma et al., 2005). Thus in relation to evidence that current medical and rehabilitative management of MND is characterised by fragmented support structures and support systems, the presence of poor patient-centred care and even patient-centred communication is further substantiated.

Contrary to the findings of this study which by and large revealed dissatisfaction with regard to the medical and rehabilitative management of MND, positive reports were elicited in terms of complementary and alternative medicine and even allopathic healthcare in the presence of HCPs who were experienced in the field of MND and/or practised abroad. Not only were these alternative professionals perceived to be better communicators than their medical counterparts, but also such individuals were

reportedly more skilled in meeting the psychosocial and emotional needs of their patients. Participants therefore reported a greater sense of support when engaging in complementary and alternative medicine, and generally perceived a more satisfactory healthcare experience in comparison to their experiences associated with medical and/or rehabilitative MND intervention.

In view of the findings related to alternative healthcare, the likelihood exists that professionals of complementary and alternative medicine are not necessarily better communicators *per sé*. Rather than good mechanistic and linguistic communication, complementary and alternative HCPs appear to utilise more of an affiliation style of communication which is warm and whole-person oriented, thereby placing the healthcare consumer at ease to express his/her thoughts, engage actively in the healthcare process, and experience a more supported healthcare encounter (Fossum & Arborelius, 2004; Leopold et al., 1996). Moreover because complementary and alternative medicine in this study was pursued by participants in response to dissatisfaction with allopathic healthcare and/or the realisation that a cure does not exist for MND, the value of an alternative approach appears to lie more in the hope that it offers healthcare consumers than the potential physiological benefits that may be derived. After all, hope facilitates coping which enhances the affect and well-being of healthcare consumers, and in return has positive outcomes in terms of patient survival (Hunt, 1991; Wasner et al., 2001). Finally although complementary and alternative medicine is an alternate to allopathy and is in many ways frowned upon by medical HCPs, it ironically appears to better meet the tenets of patient-centred care because it is congruent with healthcare consumers' personal values, encourages patient-professional interactions, and strives for patient autonomy (Astin, 1998; Fulder, 1998; Kaptchuk & Eisenberg, 1998). Moreover in this regard opportunities are also created for patient-centred communication to be achieved. As a result therefore, allopathic HCPs might thus be able to learn valuable lessons from their alternative health professional counterparts in pursuit of improving the medical and rehabilitative management of MND.

In light of the fact that both major and minor bioethical principles were undermined in the present study, sound bioethical practice was perceived to be questionable. For example further to healthcare consumers and HCPs not entertaining lengthy

discussions surrounding long-term life decisions, decision-making that did occur appeared to deny persons with MND the right to self-determination. Besides a paucity of information to make informed decisions, fragmented management services meant that there was also a weak human interface to provide participants with the emotional support that they required to engage in effective decision-making. Furthermore the absence of a MND team also meant that collaboration between HCPs was not available in order to safeguard the decision-making process and uphold the standards of ethical practice for the good of the patient. Thus rather than providing persons with MND evidence upon which to base their decisions, some paternalistic HCPs in the present study appeared to offer healthcare consumers their personal opinion and advice. In addition some family members also appeared to adopt a paternalistic attitude and make decisions for the person with MND without prior discussion or mutual agreement. Moreover despite the fact that frameworks of decision-making do not appear to include communication as a vital component necessary for making decisions, poor health communication in this study compounded by the communication impairment, compromised this aspect of ethical practice further. In the absence of shared decision-making and reciprocal communication therefore, persons with MND reported a sense of abandonment and harm, with the most apt course of action for each healthcare consumer being undermined (Cimino, 2003; Kaba & Sooriakumavan, 2007).

Questionable bioethical practice in this study further appeared to arise from medical futility and a lack of professionalism on the part of some medical and rehabilitative HCPs. The fact that few persons with MND were referred for rehabilitation for example, suggests that referring HCPs possibly perceive MND rehabilitative management to be futile in the sense that maintaining skills and promoting quality of life does not equate to a cure for this disease. Furthermore the fact that management services such as speech-language pathology intervention have not demonstrated efficacy with regard to its involvement in the field of MND, raises questions about the value and effectiveness of the healthcare services that are rendered. Moreover such concerns are rightfully justified when one considers that some HCPs did not appear competent in their ability to treat persons with MND, and therefore clinical practice based upon a professional and ethical code of conduct was questionable.

### 5.3 CONSIDERATION OF METHODOLOGICAL VARIABLES

In reflecting upon the findings of the present study and the implications that arise for future MND management, various methodological issues must first be considered. Whilst several research design and analysis limitations have been documented throughout the methodology and discussion chapters of this study, the most pertinent considerations are summarised below.

Notably the present investigation was based solely on an interview schedule that elicited the perceptions of persons with MND and the perceptions of their family members in order to explore MND management. However with regard to the fact that this interview schedule was novel and not an established measure that had been used by other researchers, the test reliability of the instrument is unknown. In the event that the present study is replicated, it is thus uncertain whether findings would demonstrate repeatability. Furthermore given that the findings of the present study did not appear to address the subtleties of communication that evidently contribute to effective health communication, the specificity and sensitivity of the interview schedule is also questionable. Moreover since patient reports and patient perceptions lack objectivity (Grbich, 2003), it is questionable whether the interview schedule used in this study was able to elicit data that reflects accurately the reality of the healthcare experience. With this limitation in mind however, given that healthcare outcomes are based on how healthcare consumers perceive and interpret their healthcare experiences, perceptual measures and thus the associated interview schedule are one of the only means for evaluating the quality of healthcare and predicting healthcare satisfaction (Arora, 2003).

Although extensive efforts were made to safeguard the reliability and validity of this study, self-report measures and patient interviews are always at risk for constraints such as social desirability bias, the misinterpretation of questions, and situational effects (Baker, 1988; Mead & Bower, 2000). It is thus possible that further to participants in this study interpreting questions differently to what the researcher had intended for example, they may have also consciously or unconsciously formulated their responses in terms of what they believed would be desirable to the researcher and socially acceptable in general. Furthermore because of the burdensome nature of MND and the fact that during the interviews the researcher may have asked questions

that evoked emotional distress, participants may have used these interactions as an opportunity to merely vent their emotions, thereby viewing the management of MND through “tainted lenses”. As a result in a further attempt to achieve objectivity, the value of the interview schedule and the interviews with persons with MND and their family members may have been heightened if probes were included that also aimed to elicit information from participants in terms of what they perceived to be positive aspects relating to MND management. After all an awareness of the perceptions that were related positively to the management of MND, may have assisted in developing a more holistic and patient-centred framework of ideal MND service delivery that is better suited to the needs of MND healthcare consumers.

A further limitation of this study relates to the fact that when participants were probed about their relationship with HCPs it was considered as a single construct. In other words despite the possibility that persons with MND may have consulted several HCPs, perceptions were elicited in terms of participants’ overall impressions regarding management received from these professionals as a group. Different perceptions may however have arisen for the different HCPs that were consulted. According to Arora (2003) therefore, data analysis of perceptual measures should include participants’ ratings of each HCP’s performance separately, as well as consideration of the findings that arise from a one-to-many correspondence. Furthermore given that the healthcare encounter comprises a combination of contributions made by both patients and professionals (Arora, 2003), and that the findings of this study revealed that HCPs are not immune to the distress caused by MND, a more comprehensive management framework for the benefit of healthcare consumers and healthcare providers might further be achieved by also considering the perspectives of MND healthcare practitioners.

Irrespective of both logistical and reliability considerations having prevented the researcher from complementing interview findings in this study with an intended observational component, and the literature highlighting the fact that observations applied to a once-off consultation are not sensitive to aspects of the patient-professional relationship (Mead & Bower, 2000), no one evaluative healthcare approach can account for the complexity of patient care (Mead & Bower, 2000; Zandbelt et al., 2005). To this end the design of the present study may have

nonetheless been improved by including a combination of perceptual and observational measurements, whereby participants reported their experiences of different healthcare encounters, as well as permitted the researcher to observe different patient-professional interactions during healthcare consultations. In addition because the patient-professional relationship is said to develop over successive consultations and not a single healthcare encounter, it cannot be assumed to be stable across visits (Arora, 2003; Mead & Bower, 2000). And thus rather than a cross-sectional design which allows for “snapshots” of the patient-professional relationship to be gleaned (Arora, 2003), the value of the present study could have been enhanced through the use of longitudinal evaluations that investigate MND management of each Unit over a defined period of time.

In view of the small sample size utilised in this study, the findings obtained cannot be generalised to the broader MND population and clinical applicability is also restricted (Arora, 2003). This limitation is acknowledged despite the fact that the researcher wished to obtain detailed information about each MND Unit, deeming a large sample size impractical for the nature of the present study. Furthermore the use of criterion sampling in this study resulted in the findings being more representative of a homogeneous group of persons with MND rather than the MND population at large, again limiting opportunities for generalisability. In replicating the present study using a larger sample size therefore, it is likely that the results would give rise to findings that are more representative of the MND population. Moreover more precise research undertakings that have more refined aims may be initiated by refining the inclusion criteria of the sample population. For example unlike the wide variability in terms of time since diagnosis evident in this study, future studies may wish to investigate a sample of persons with MND that share more similar demographic features. In addition researchers may also wish to specify more stringent criteria in terms of the type of MND included in the study, as well as the degree of severity of the communication impairment.

In considering that a variety of strategies were employed throughout this study to safeguard its trustworthiness, the fact that data analysis was reliant upon qualitative methods gives rise to the possibility that researcher bias may have come into play (Grbich, 2003). The use of more than one researcher and a researcher other than the

one who designed the study and has a vested interest in the project, may therefore function to further protect the reliability and validity of the data collection process and data analysis phase.

Finally given the diversity and unpredictability of human nature, and the fact that such variability makes it difficult to achieve complete control and consistency in human research (Grbich, 2003; Silverman, 2000), the researcher was unable to predict and account for all confounding variables that may have impinged on participants' perceptions regarding MND management. And thus while some of the limitations and inconsistencies in this study were inevitable, every effort was taken to control for predictable variables and achieve a high degree of rigour in the research method.

#### **5.4 IMPLICATIONS OF THE STUDY**

The findings of the present study revealed that not only does the medical and rehabilitative management of MND appear to lack patient-centred care and patient-centred communication, and hence influence bioethical practice, but also support networks are evidently fragmented such that healthcare consumers tend to find solace in pursuing complementary and alternative medicine. In response to these findings and an attempt to elicit more positive perceptions regarding the medical and rehabilitative management of MND in the future, a framework of ideal service delivery for MND healthcare consumers has been proposed (Figure 6). This framework accounts for the inadequacies that were perceived by both persons with MND and their family members, while simultaneously bearing in mind management guidelines documented in international texts, and the fact that these recommendations might only be feasible in this country if they are considered in relation to the current limitations and restrictions placed on South Africa's healthcare system. In an effort to thus operationalise this new framework and begin to see change in a positive direction towards more satisfactory MND management, the various clinical, theoretical and research implications that are pertinent to this study are considered in the write-up that follows.

##### **5.4.1 Implications for Clinical Practice**

In relation to the fact that participants as a whole perceived the medical and rehabilitative management of MND to be unsatisfactory, implications arise for HCPs

and specifically speech-language pathologists with regard to their clinical endeavours within the MND healthcare arena.

Related to the fact that patient-centred communication was absent in the present study, the need for improvement in this area of practice is evident, particularly when one considers that patient-centred communication improves patient satisfaction regarding the healthcare experience, reduces patient distress, and improves overall health outcomes (Post et al., 2002). Moreover given that participants in this study further perceived the communication impairment to influence the medical and rehabilitative management of MND, beyond instilling patient-centred communication within the realm of MND management, health communication from the perspective of the communication impairment also needs to be addressed.

Given that a large component of health communication literature focuses on training HCPs in core communication skills so that they can listen actively for example, as well as address the feelings of their patients in order to facilitate a more open and direct patient-professional dialogue (Post et al., 2002), such programmes possibly need to be directed specifically towards HCPs involved in the management of MND. However in order to satisfy the needs of MND healthcare consumers in full, communication training programmes not only need to be modified and made more disease-specific so as to meet the nuances that arise within a MND healthcare discourse, but also HCPs need to be trained and provided with the skills that are necessary for engaging with patients who present with a communication impairment. Drawing on the literature from aphasia and the fact that the external environment is often hostile towards communication and the communicatively impaired individual (Parr & Byng, 1998), HCPs need to equip themselves with the knowledge and skill necessary for creating a competent environment that will enhance and reveal the competence of the person with MND. In-service communication training and workshops that perhaps form a mandatory component of continued professional development, may provide invaluable opportunities for all qualified HCPs involved in the management of MND to be equipped with the skills that are required for communicating effectively with healthcare consumers who are communicatively compromised. Moreover at a tertiary level of training, rigorous efforts are required to not only educate all healthcare students theoretically about healthcare in the presence



of a communication impairment, but also practical training is required to ensure that learners achieve competency in their abilities to engage appropriately with such healthcare consumers. In this regard therefore, educators and tutors at tertiary institutions need to acquire confidence in teaching health communication skills and evaluating health communication curricula that aim specifically to address healthcare consumers with a communication impairment (Duffy et al., 2004).

In highlighting the value of HCP communication training from the perspective of the communication impairment, speech-language pathologists are urged to recognise that their inherent knowledge and skill places them in a unique position to facilitate such training efforts. Whether speech-language pathologists choose to serve as a consultant, provider of resources, or supervisor when engaging in HCP communication training, they ultimately play a vital role in providing the communicatively impaired individual with greater communicative access. In addition a simultaneous opportunity prevails for the profession of speech-language pathology to be made more visible and meaningful to other professionals and the public at large (Kagan, 1998b). As a result therefore, in order to ensure that communication skills training for persons involved in the management of MND becomes a reality, the onus rests with speech-language pathologists to demonstrate to healthcare administrators and healthcare funders the potential benefits and cost effectiveness of such training, particularly with respect to the communication impairment and the associated health outcomes for the communicatively impaired population.

Further to the fact that healthcare consumers are often ineffective communicators and in need of patient communication training (Post et al., 2002), the results of the present study suggest that persons with MND might also benefit from training which accounts for the communication impairment. However since the progressive nature of MND implies that complete rehabilitation of impaired communication skills is questionable, and that in the presence of defective communication participants in this study were not empowered to interact with HCPs during healthcare encounters, such individuals need to be provided with communication strategies that move beyond disability and the impairment level, and encourage social participation. Thus by extrapolating the tenets of a social model of disability as documented in the aphasia literature, the possibility exists for speech-language pathologists to provide persons with MND

opportunities for genuine social participation, thereby empowering them and reducing the social consequence of the communication impairment such that they are provided with the key to access services within their environment (Kagan 1998b).

Since it is thus evident that the profession of speech-language pathology plays an important role in the management of MND (Leigh et al., 2003), it is ironic that in the case of the present study speech-language pathologists lacked clinical involvement and were omitted from the referral network. However given that such omissions may be related to an absence of a position statement that documents the precise role of this profession in the management of MND, implications prevail for speech-language pathologists in terms of developing intervention policy documents and clinical protocols that will inform rigorous practice. Furthermore from a South African standpoint, as a sign of its endeavour to shape moral behaviour, The South African Speech-Language and Hearing Association needs to consider developing its own policy documents and position statements that account for more than neurodegenerative conditions in general, but also stipulate exact clinical guidelines for the management of specific disorders such as MND. Consequently if speech-language pathologists who work in the field of MND unite as a group and formalise their involvement in this area of practice, the possibility exists to acquire an improved clinical identity and subsequently secure a position within the referral network, such that all persons with MND are referred for speech-language pathology intervention. Moreover in this instance healthcare consumers may even begin to express greater satisfaction with regard to speech-language pathology services, thereby functioning to enhance the overall credibility of the profession.

In order to further ensure the credibility of speech-language pathology intervention within the domain of MND management, it is vital that speech-language pathologists prove the profession's worth by engaging in efficacy and effectiveness studies that are of a high degree of specificity. If speech-language pathologists are able to prove the value of the services that they render, then it is possible that the scepticism and futility that other HCPs may have surrounding the profession might be abolished, thereby instilling within these professionals a more positive attitude that is conducive to more widespread patient referrals. Furthermore in order to ensure that HCPs involved in MND management are exposed to the findings of studies that highlight the efficacy

and effectiveness of speech-language pathology interventions, speech-language pathologists are encouraged to broaden their publication boundaries and publish their work in formal texts and journals that are not specific to their profession, but are rather accessible to the numerous individuals that comprise the MND healthcare team.

Similar to the findings in terms of few persons with MND receiving speech-language pathology intervention, the fact that individuals were also not referred for other types of supportive therapies central to MND healthcare, may imply either an ignorance or paucity of knowledge on the part of referring agents with regard to available management services. A need is therefore apparent to heighten the awareness of professionals regarding the fact that because pharmacological interventions might only alter disease progression (Miller et al., 1997), the value of a combination of patient-specific rehabilitative therapies that aim to assist in the maintenance of skill and promotion of quality of life cannot be denied (Gelinias, 1999a). As a result HCPs and in particular rehabilitative professionals, need to become entrepreneurs whereby they identify professional opportunities to demonstrate their skills to healthcare providers, healthcare funders, and healthcare consumers, so as to promote the value and cost-effectiveness of their services and thus secure a more comprehensive referral and intervention network (Pietranton, 1998).

Arguably however even with strategies in-situ to enhance the knowledge and awareness of MND team members regarding management services, comprehensive MND healthcare is still likely to be compromised by virtue of the fact that within the South African context current MND management occurs in a resource-restricted environment. Moreover since MND affects fewer patients than any of the better known neurodegenerative conditions and curative interventions are currently unavailable, there is a limited market for the involvement of financially independent multinational pharmaceutical companies (Oldendorf & Bruijn, 2004). There is thus little to no financial imperative and sustained financial support surrounding the management of MND. As a result HCPs are encouraged to conceptualise innovative strategies that will promote MND service delivery, maximise existing resources, as well as mobilise new services. In addition through widespread advocacy, education, and fundraising initiatives, one may be able to dispel the negative societal attitudes created by the media in terms of MND being a helpless disease (Leigh et al., 2003).

Also societal awareness campaigns may be able to lure a custodian of care who would be willing to “adopt” MND and provide the financial backing that is essential for comprehensive management that as yet cannot be justly provided at a national or state level.

Apart from engaging in intensive advocacy and education endeavours for financial purposes, such efforts may motivate members of the public to be more supportive towards the plight of persons with MND. In turn this community involvement may assist individuals with MND and their family members in experiencing a greater sense of self-control and mastery to effect change in their own life (Hallowell & Chapey, 2001). For persons with MND therefore, they may for example feel more empowered to demand management services that might be denied for any particular reason, and may even exercise their right to obtain a second opinion or consult a new HCP in the event that a lack of quality service delivery is perceived. Hence such efforts may instil a culture of consumerism within healthcare consumers, such that they are no longer passive recipients of MND management but rather empowered arbiters of their own healthcare.

Further to the efforts on the part of HCPs to market their services and advocate for persons with MND, MND support organisations are also encouraged to engage in similar practice. Such endeavours may aid in forging collaborative partnerships and improved networks between HCPs and support organisations, thereby providing healthcare consumers with enhanced opportunities for more comprehensive MND management. In addition greater clinical awareness and collaboration between healthcare providers and support organisations may encourage the development of a MND database, whereby healthcare consumers can be assisted in obtaining the necessary information and contact details of a wide variety of management services, as well as be linked to a number of pre-approved and efficacious MND Internet sites. Finally it should be noted that greater collaboration, communication, and networking between healthcare providers and support organisations may further function to not only provide support and more comprehensive management to healthcare consumers, but also provide a supportive environment for HCPs who are required to engage in the burdensome nature of MND healthcare on a daily basis. After all HCPs need to practice within a supportive environment so as to preserve their own well-being in

order that they are able to help their patients to achieve and maintain a satisfactory level of health (Dunning, 2005).

Finally in response to the fact that the bioethical practice of many HCPs was deemed questionable in this study, the overlap between patient-centred care and patient-centred communication suggests that improvements in these areas of healthcare may in turn facilitate improvements in the bioethical management of MND. Thus by attempting to overcome the inadequacies of patient-centred care and patient-centred communication by engaging in patient advocacy, improving societal awareness, promoting health communication training, and engaging in efficacy and effectiveness studies, opportunities arise for enhancing the professional and ethical conduct of HCPs that contribute to sound bioethical MND management.

#### **5.4.2 Theoretical Implications**

In addition to practical suggestions for improving the medical and rehabilitative management of persons with MND, the findings of this study also have important implications for the development of theory.

Although patient-centred communication is ideal in theory because it facilitates the implementation of patient-centred care, this study has revealed that it is in fact a mere philosophy of healthcare with no practical guidelines in terms of how one can actually achieve a patient-centred style of communication. Thus the theory of patient-centred communication needs to be made more explicit in terms of how HCPs might modify their communicative interactions with patients in order to elicit patient perceptions, acknowledge the psychosocial context, and share power and responsibility for example (Epstein et al., 2005), whilst also ensuring that these modifications are feasible within each healthcare encounter. Moreover since achieving these patient-centred ideals relies on communication between the HCP and the patient, and in theory communication is a bi-directional process (McLaughlin, 1998), implications arise in terms of extending the tenets of patient-centred communication such that the communicative behaviours of healthcare consumers are also included. After all health communication is not generated by the communicative behaviours of HCPs alone, but also by those of healthcare consumers (Arora, 2003).

Further to the theoretical inadequacies noted in terms of patient-centred communication, findings from this study also revealed that in general there appears to be a paucity of health communication literature that considers specifically the communicatively impaired population. However as a result of the knowledge and skill of speech-language pathologists in this area of healthcare, these professionals play a fundamental role in developing theories of health communication that contribute to effective healthcare in the presence of a communication impairment. Thus in the present situation HCPs need to work on developing health communication theories that not only address the actual communication impairment, but also utilise the ideals of patient-centred communication as a basis to extend such principles and include the fundamental elements inherent to theories of communication disability. For example following on from the aphasia literature and the use of a social model of disability, speech-language pathologists involved in the management of MND might develop theories of health communication that not only aim to address defective communication components (e.g. reduced speech intelligibility), but also aim to reveal the competence of the person with MND and empower him/her to participate in his/her own healthcare and in the community in general (Pound et al., 2006). In addition such theories also intend to reduce the psychosocial consequences of the communication impairment, allowing the person with MND the opportunity to experience communicative success and control within his/her own healthcare (Kagan, 1998a). While patient-centred communication may still be in its infancy, the principles of this construct nonetheless need to be refined and adapted so as to ensure that the theory can be operationalised in the presence of communicatively impaired healthcare consumers, in pursuit of the ideals that bring about patient-centred care.

With respect to the fact that the current study revealed that international management recommendations are not always practical within the South African healthcare arena, HCPs and even healthcare students are called to think critically and challenge the current healthcare system in order that more innovative service delivery models are devised. In other words in line with the lack of interventions and fragmented patient-centred care evident in this study, HCPs are encouraged to consider the appropriateness of current healthcare models for the management of MND in the present context. For example unlike the multidisciplinary team that is recommended as the ideal for MND management (Leigh et al., 2003), in the South African setting it

appears that a transdisciplinary model of intervention may better meet the needs of healthcare consumers. Furthermore while international literature suggests that HCPs advocate for holistic MND management in the form of comprehensive hospital based teams and clinics (Leigh et al., 2003), for the time being motivations to obtain community-based interventions and home healthcare for example, may be more feasible and more practical in relation to South Africa's current healthcare climate. Consequently HCPs involved in the management of MND need to engage in research to determine whether the alternate approaches to MND service delivery that are offered in this study are effective in meeting the needs of healthcare consumers, as well as accommodating of the limitations of the healthcare setting. Thereafter such findings need to be documented formally and theories need to be formulated in an attempt to begin creating a South African-specific MND management protocol that is patient-specific, context-suitable, and evidence-based, and possibly even lay the foundation for MND best practice in South Africa.

Despite the fact that literature pertaining to MND states that the emotional well-being of the individual and the family should be preserved (Leigh et al., 2003), an acknowledged and efficacious approach for providing support to individuals does not appear to be entwined within the management of MND. Such findings thus imply that HCPs involved in MND management need to formalise a theoretical and practical approach that can provide MND healthcare consumers with the support that they require. Since the oncology literature documents the merits of supportive care whereby patients and families are placed at the centre of their treatment and empowered to engage in their own healthcare (Ahmedzai et al., 2004; Fincham et al., 2005), and findings of this study indicated that MND healthcare consumers seek similar supportive variables, HCPs are provided with a framework upon which to modify and expand the theory of supportive care in order to account for the needs of persons with MND and their families. In addition because the role of HCPs in the management of MND is to educate, counsel and advise rather than cure, the need for a supportive theory of care is further highlighted.

In a further attempt to establish South African-specific MND management guidelines, the results of this study demonstrate that persons with MND and their family members not only find value in complementary and alternative medicine, but also the

behaviours of such alternative professionals were perceived in a more positive light. Implications thus arise for professionals of MND healthcare to consider developing an integrative theory of management that combines alternative approaches to medicine with traditional medical and rehabilitative management (Hollenberg, 2005). Such an integrative healthcare system is likely to facilitate the development of a comprehensive MND management approach, given that healthcare consumers would be provided with a biomedical disease model that offers autonomy, self-preservation and hope, and further accounts for personal values and beliefs (Hollenberg, 2005; Kaptchuk & Eisenberg, 1998).

Finally with respect to the bioethical component of decision-making, it was evident in this study that persons with MND were denied the right to self-determination. However because effective decision-making is characterised by warmth, empathy, and a trusting healthcare experience (Arora, 2003; Bruera et al., 2001), and it was demonstrated in the application of Bliss and While's (2003) decision-making framework that health communication is fundamental to decision-making, implications are apparent for developing a theory of decision-making that incorporates interpersonal care and health communication. Thus similar to the documented clinical implications, if greater efforts are made to implement patient-centred care and patient-centred communication while also considering the communication impairment, then it follows that bioethical practice will also be enhanced and so too the process of decision-making.

### **5.4.3 Implications for Future Research**

Although the previous sections on clinical and theoretical implications highlight areas of future research required in order to modify existing theories and practices or develop new ones, the following discussion briefly documents the most significant research possibilities that arose from the present study.

Given that the present study was solely a descriptive study that explored a small sample of participants' perceptions pertaining to MND management, more in-depth research is indicated in this regard. For example because it cannot be said with certainty that the findings of this study can be applied to larger groups of persons with MND around the country and across cultures, this study needs to be replicated using larger samples and different cultural groups to determine whether similar MND



management trends would be yielded throughout South Africa. Moreover the inclusion of observational measures and the elicitation of HCPs' perceptions may function to cross-check the perceptions of MND healthcare consumers as well as enhance the depth and value of findings that are yielded in future studies.

Although the findings of this study are indicative of management practice specific to persons with MND, similar results may be common to other neurodegenerative conditions. Consumers of this literature are therefore cautioned from making the assumption that persons with MND are significantly mismanaged in relation to other conditions. This study should thus be repeated using different clinical populations to ascertain any commonalities that may be inherent to the management of individuals with different neurodegenerative disorders. Moreover by repeating this study using individuals with Parkinson's disease and Alzheimer's disease for example, the researcher may be offered the opportunity to draw on the strengths of clinical practice from these various conditions, in order to formulate a more integrated approach to MND management.

In view of the fact that the interview schedule used in this study had not been used previously and had not been validated, rigorous research is required to determine whether the tool was sensitive to the aims of the present study. Further research regarding its reliability and validity will also aid in informing future researchers as to whether the schedule as a whole or even parts thereof, would be useful for future investigations. Furthermore with respect to the proposed framework of ideal service delivery for MND healthcare consumers, detailed investigations are required to determine the value, effectiveness, and feasibility of utilising this structure for the management of MND. Research in this area is essential if this framework is to be utilised in the future, given that at present it is merely a proposal for ideal MND management that as yet has not been tested empirically.

In acknowledging that the design of this study elicited participants' perceptions in a once-off manner, further research is required to ascertain the stability of perceptions over time. Since one cannot predict whether perceptions of patients will stabilise or change over a six-month period for example (Silverstein et al., 1991), the need for the present study to adopt a longitudinal design where management patterns are analysed over time is reiterated (Arora, 2003).

Despite the fact that this study included the perceptions of family members regarding MND management, little attention was paid to the needs of these individuals and to what they as caregivers require throughout the course of the MND journey. Moreover since the needs and goals of persons with MND and their caregivers differ from one another over the duration of the disease (Trail et al., 2003), and to date there are few studies that have investigated the psychological status and attitudes of MND caregivers, research undertakings in this area are indicated.

Finally in accordance with the fact that the results of this study indicated that participants' perceptions provide a valuable means for informing improvement in MND management, outcomes research confirms the importance of the patient's point of view as central to clinical medicine and a fundamental method for achieving patient-centred outcomes (Sullivan, 2003). However because evidence-based medicine focuses on offering healthcare providers the best evidence available regarding the most appropriate treatments for different patients, the scientific ideals of healthcare cannot be undermined (Bensing, 2000). Hence in the case of the present study, speech-language pathologists for example need to ensure that the treatments which they prescribe are not only perceived as acceptable by MND healthcare consumers, but have also undergone rigorous empirical testing to ensure their efficacy and effectiveness. In an attempt therefore to align subjective and objective medicine (Bensing, 2000), future MND studies need to combine evidence-based medicine and patient-centred care. In addition such studies need to incorporate health communication, given that communication plays a key role in bridging the gap between clinical practice and clinical science (Bensing, 2000).

## **5.5 CONCLUDING COMMENT**

In acknowledging that persons with MND and their family members perceived the medical and rehabilitative management of MND to be inadequate, this study has challenged current healthcare paradigms and raised more possibilities than certainties. Moreover since the pathogenesis of MND remains enigmatic, there is one certainty that until such time as a cure is discovered, HCPs will need to pay greater attention to symptomatic treatments in order to optimise quality of life and compassionately journey with the patient and family from active life to death (Francis et al., 1999).

In response to the fact that the entire system of serving patients has been reformed (Johnson & Jacobson, 1998b), the scientific nature of evidence-based medicine must now be aligned with the subjective contributions of patient-centred care (Sullivan, 2003), whilst simultaneously ensuring optimal healthcare in the presence of managed care demands and financial cutbacks (Fossum & Arborelius, 2004). Furthermore in keeping with these transformations, healthcare providers are therefore urged to undertake a major effort to overhaul the manner in which they deliver healthcare services to patients (Cornett, 2006). Consequently while it has been demonstrated that MND management stems from an overlap of patient-centred care, patient-centred communication, and bioethical practice, requirements for service delivery reform mean that quality MND healthcare can only be attained if current practice is compatible with the needs of healthcare consumers, as well as those of healthcare providers and healthcare funders (Pietranton, 1998).

In conclusion since the medical and rehabilitative management of MND is therefore a complex endeavour that is ripe for additional scientific inquiry, possibilities clearly exist to destroy barriers to satisfactory healthcare and thus improve patient perceptions and the overall quality of care for both persons with MND and their family members. However because the nihilistic attitude of HCPs regarding MND healthcare appears to be more terminal than MND itself, healthcare providers are urged to shift their mind-set regarding the medical and rehabilitative management of persons with MND and their family members. After all in the absence of a cure and the inability to alter the pathology of the anterior horn cell (Mulder, 1980), at the very least MND healthcare consumers desire autonomy, care, comfort, and support to enhance their quality of life and overcome the obstacles of living with an inexorable illness (Sufit, 1997). And thus, *“In knowing that it is fatal we just want him to give us support and let us know that he acknowledges our feelings. This experience is after all not only about just paying for the health practitioner’s advice, he must care too”* (Participant in this Study).

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## APPENDIX A

### FRENCHAY DYSARTHRIA ASSESSMENT SCORE SHEET

**DYSARTHRIA ASSESSMENT**  
SPEECH THERAPY

LAST NAME \_\_\_\_\_ D.O.B. \_\_\_\_\_  
 FIRST NAME \_\_\_\_\_  
 ADDRESS \_\_\_\_\_

Date \_\_\_\_\_  
 Hospital No. \_\_\_\_\_  
Atfix Patient Identification Label

**INFLUENCING FACTORS**  
Cross if contributing to speech disorder

HEARING \_\_\_\_\_  
 SIGHT \_\_\_\_\_  
 TEETH \_\_\_\_\_  
 LANGUAGE \_\_\_\_\_  
 MOOD \_\_\_\_\_  
 POSTURE \_\_\_\_\_  
 RATE (Words/Min.) \_\_\_\_\_

	REFLEX		RESP.		LIPS		JAW		PALATE		LARYNGEAL		TONGUE		INTELL.	
	a	b	c	d	e	f	g	h	i	j	k	l	m	n	o	p
Normal Function	NORMAL FUNCTION															
NO FUNCTION	NO FUNCTION															
Cough																
Swallow																
Drinks/Choo																
At Rest																
In Speech																
At Rest																
Spread																
Seal																
Alternate																
In Speech																
At Rest																
In Speech																
At Rest																
Frustr.																
Maintenance																
In Speech																
Time																
Pitch																
Volume																
In Speech																
At Rest																
Profusion																
Elevation																
Lateral																
Alternate																
In Speech																
Words																
Sentences																
Conversation																

**SUMMARY**

SENSATION \_\_\_\_\_  
 UPPER LIP ☹ \_\_\_\_\_  
 UPPER LIP ☹ \_\_\_\_\_  
 TONGUE TIP \_\_\_\_\_

**RECOMMENDATIONS**

SUBJECTIVE REPORT ON SENSATION \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

SIGNED \_\_\_\_\_

4284 First Street  
 2007

## **APPENDIX B**

### **ADMINISTRATION AND SCORING OF THE FDA**

The FDA comprises eleven sections including a) reflex, b) respiration, c) lips, d) jaw, e) palate, f) laryngeal, g) tongue, h) intelligibility, i) rate, j) sensation, and k) associated factors.

The researcher administered the first eight subsections of the assessment by asking the person with MND to complete a definitive set of tasks as set out in the FDA manual. The researcher first demonstrated each task, and a final score was recorded on the participant's second attempt at the task. Scoring was completed according to the FDA manual, where a 9-point rating scale was used to score the participant's responses for each subtest. The FDA manual depicts the 9-point scale in terms of letters of the alphabet, where the letter "a" indicates maximum function and the letter "e" represents no function. The results were recorded on a bar graph with the 9-point scale on the vertical axis, and the individual tests of the eight subsections along the horizontal axis. For each subtest a vertical line was drawn up to the appropriate point along the 9-point scale, so as to reflect the severity rating of that particular task. On completion of the assessment a pattern of the participant's disorder was visibly clear, revealing areas of speech which were most and least affected. Although the possibility exists on the FDA to evaluate speech performance halfway between each letter of the alphabet (a-e) thereby resulting in a 9-point scale, there are no alphabetical letters that correspond to these intermediate points. For the purpose of the present study therefore, the alphabetical letters on the 9-point scale were translated into numerical values, allowing a number to be attributed to each intermediate point. The lowest score "e" on the FDA score sheet was thus rated as 1 and indicated no function, while the maximum score "a" was rated as 9 indicating normal function.

The subtest of intelligibility involved rating the participant's production of words, sentences and conversation. In order to score the subtest accurately, the participant's production of words, sentences and conversation was tape recorded and played back to an independent speech-language pathologist. The speech-language pathologist was required to listen to the tape recording of the words and sentences and indicate what he/she had heard. Thereafter this interpretation was compared to the actual words or sentences that the participant had been required to produce. Scoring was made according to the guidelines in the FDA manual, grading participants according to the number of words interpreted correctly by the listener. In terms of rating conversation, the independent speech-language pathologist was required to

listen to a recording of the participant's spontaneous speech and rate it according to five possibilities outlined in the manual. These five rating options ranged from no abnormality to the patient being totally unintelligible (Enderby, 1984).

The final component of the FDA comprises the three remaining subsections of rate, sensation, and associated factors, all of which are discussed below. For each of these sections, space is provided on the FDA score sheet to record the findings.

*Rate* of conversation was analysed from a spontaneous speech recording, whereby the number of words per minute was counted and compared to normative data provided in the FDA manual.

*Sensation* tasks were performed to identify participants with gross sensory loss. The FDA manual provided simple guidelines in order to conduct a short test that yielded information regarding sensation.

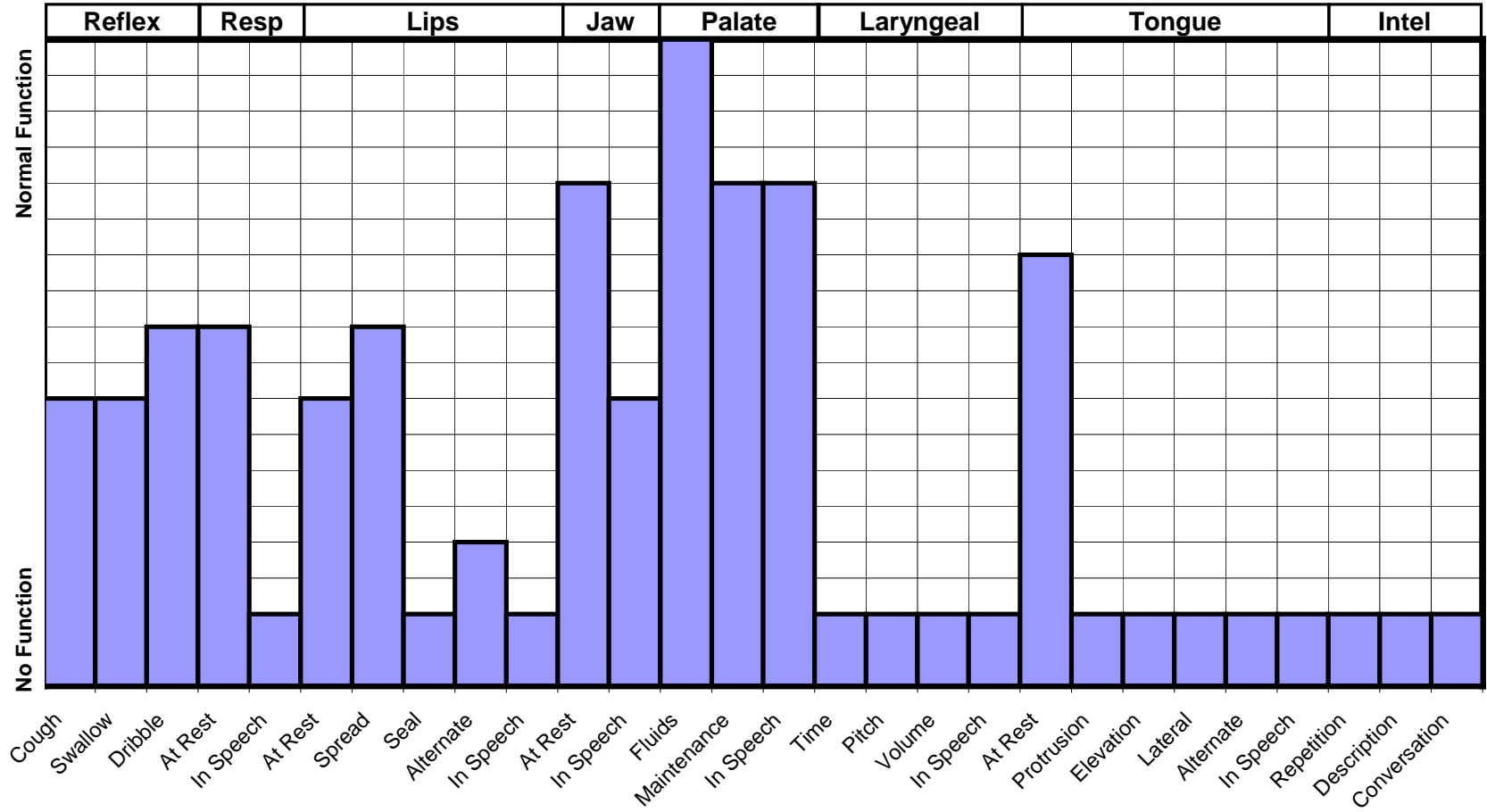
*Associated factors or influencing factors* include hearing, sight, teeth, language, mood and posture, and required the researcher to establish whether any of these factors affected or contributed to the participant's overall speech performance. The researcher was required to ask the participant whether he/she had any concerns relating to hearing and sight, as well as observe the participant and record any associated observations. In terms of teeth, the researcher was required to examine the teeth and/or dentures of the participant, as well as note the condition of the teeth and gums. Expressive and receptive language was evaluated on the basis of the researcher's interactions with the participant, noting the need for a detailed language assessment. Whilst it is acknowledged that such a simple observation is by no means a comprehensive assessment of expressive and receptive language, additional language testing was excluded from the study on the basis that language competency is relatively intact in individuals with MND (Francis et al, 1999). Mood was evaluated based on the researcher's perception of whether or not the participant demonstrated insight into his/her condition, and whether he/she was motivated and cooperative during the assessment. The final factor of posture was based on an observation by the researcher, where symmetry of the chest and head was noted, along with head control when speaking as well as any visible tension in the head and shoulders.

**APPENDIX C**

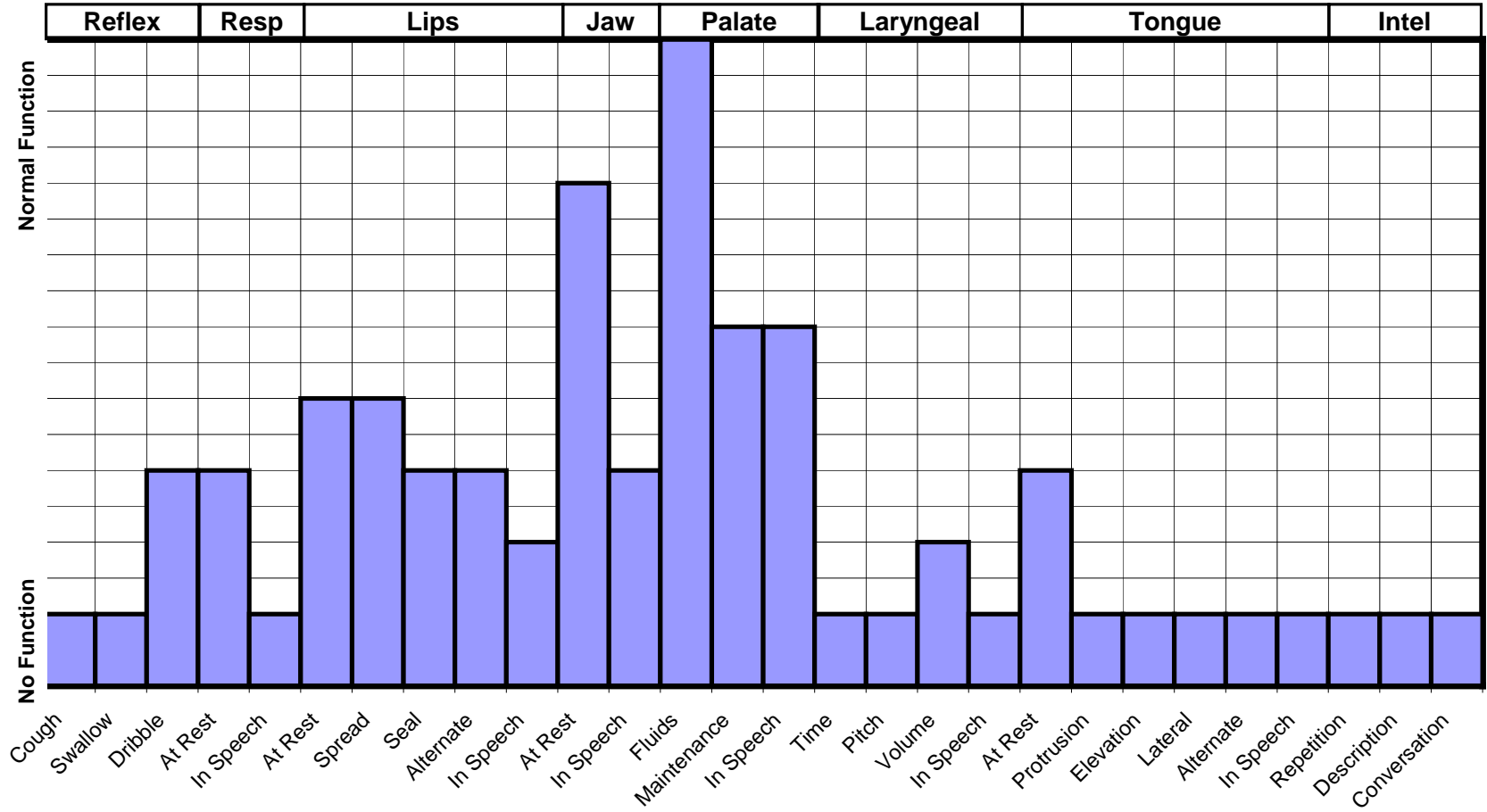
**GRAPHICAL REPRESENTATION OF PERFORMANCE ON THE FDA**



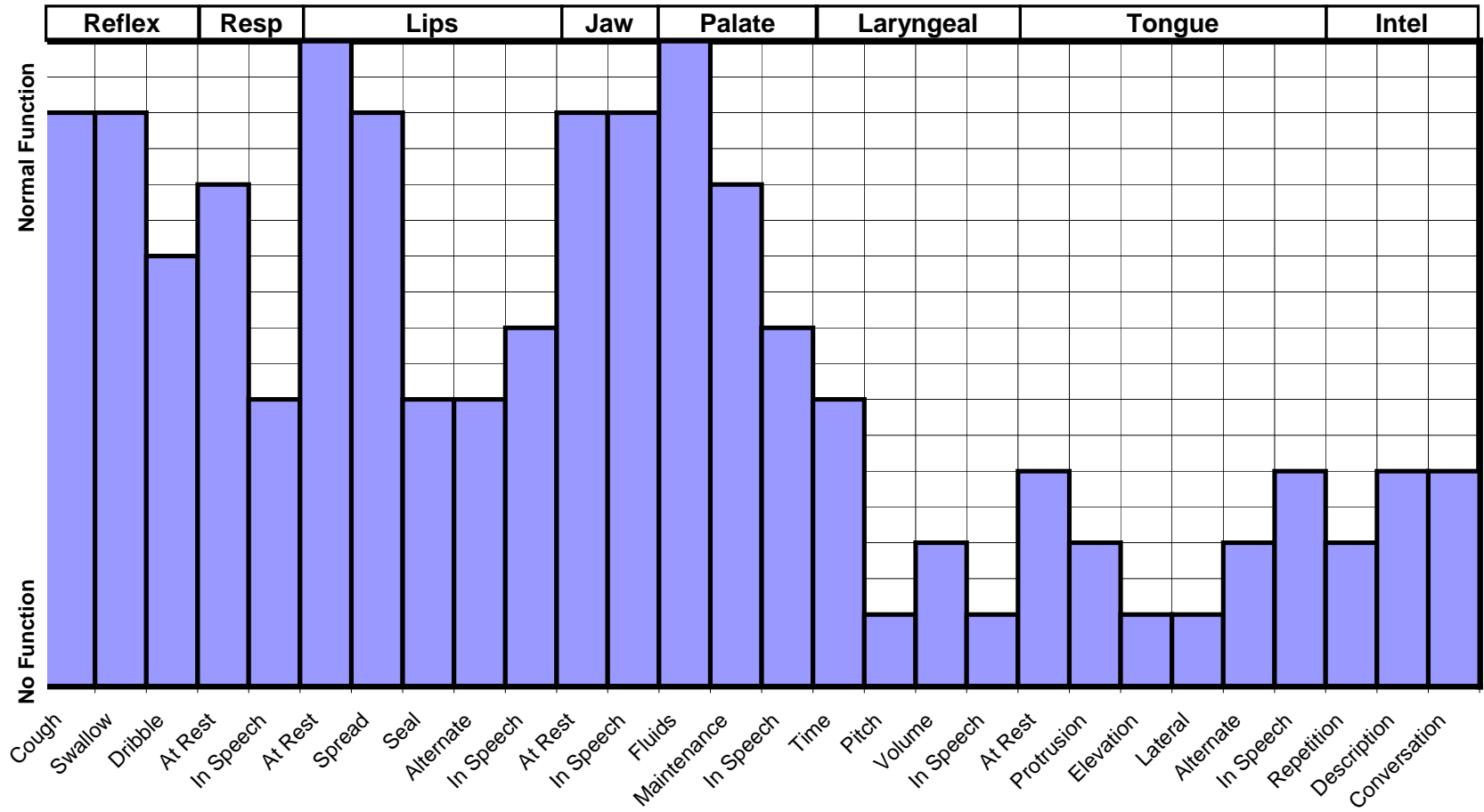
Frenchay test results - Unit 1



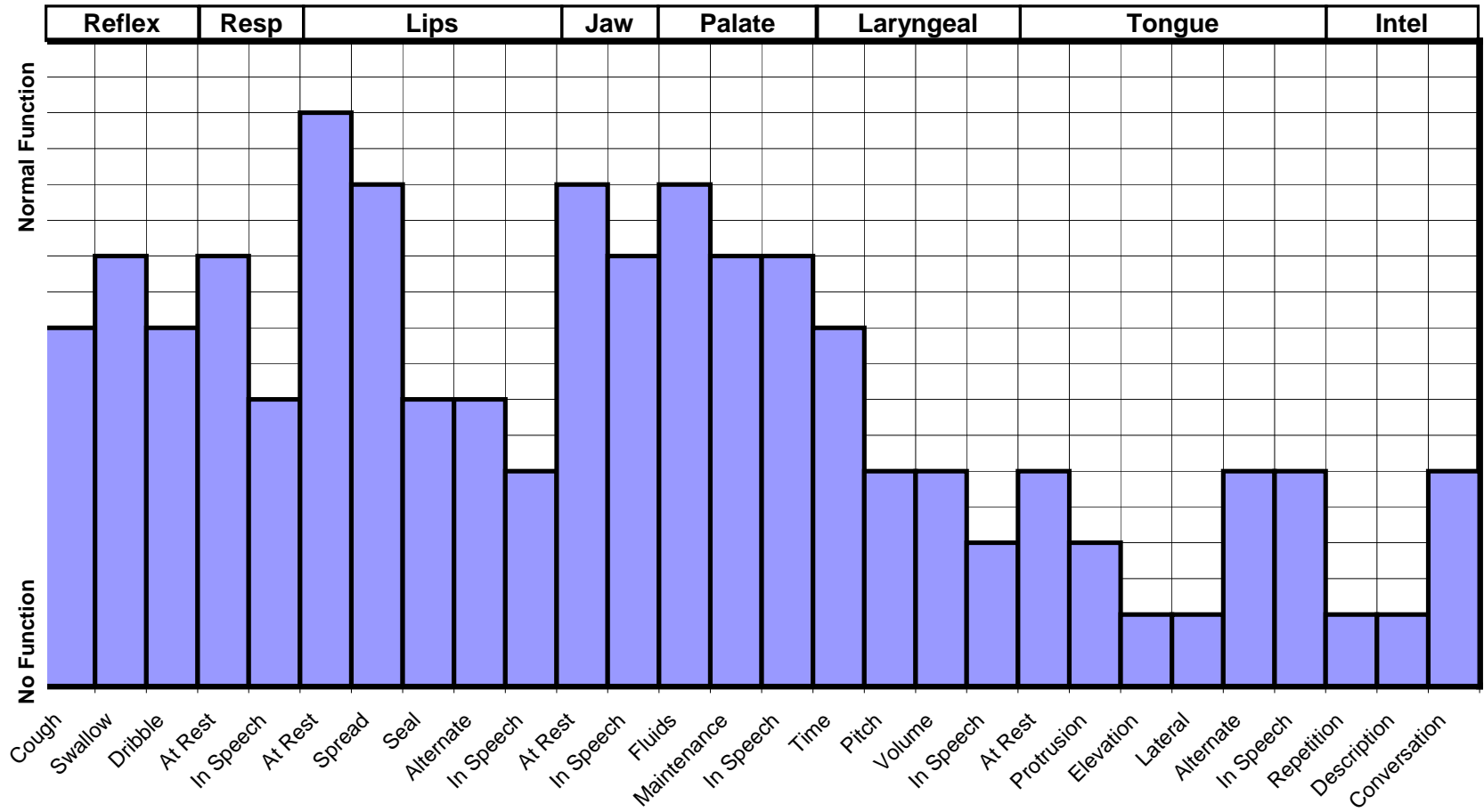
Frenchay test results - Unit 2



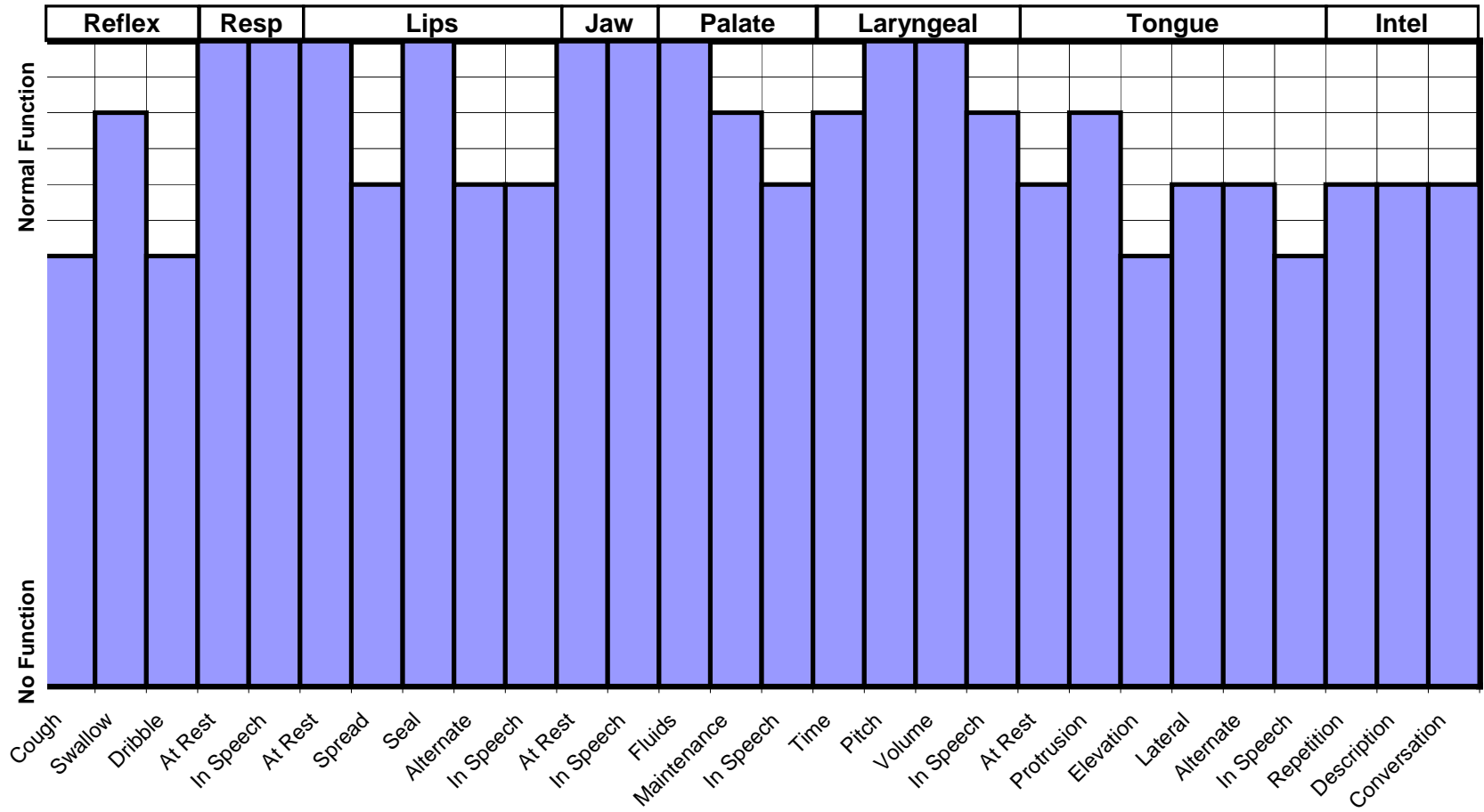
Frenchay test results - Unit 3



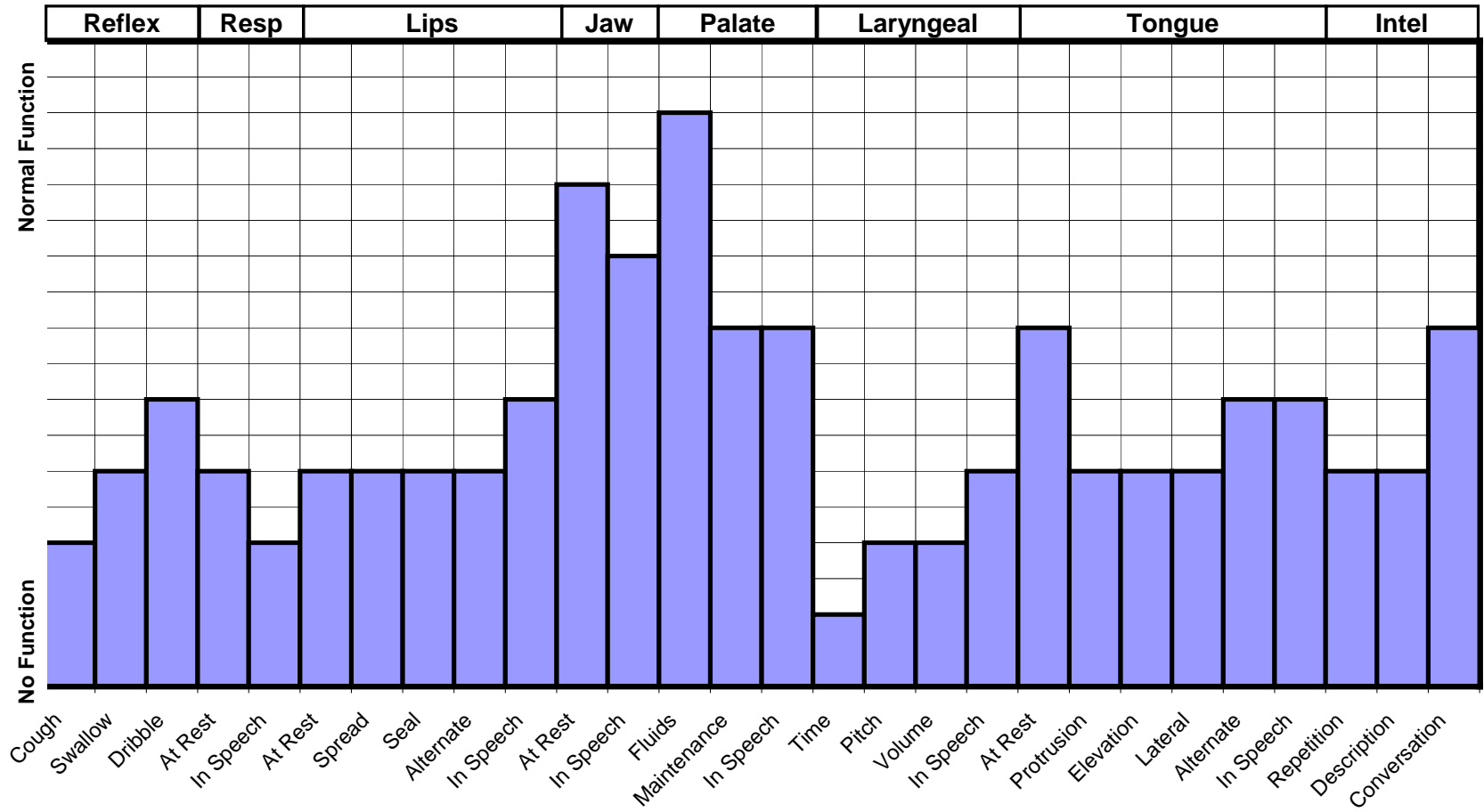
Frenchay test results - Unit 4



Frenchay test results - Unit 5



Frenchay test results - Unit 6





**APPENDIX D**  
**RESEARCH CLEARANCE CERTIFICATES**

**UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG**

Division of the Deputy Registrar (Research)

**HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)**

R14/49 Marett

**CLEARANCE CERTIFICATE**

**PROTOCOL NUMBER M040420**

**PROJECT**

overall management of persons with amyotrophic Lateral Sclerosis (ALS)

The impact of communication impairment on the

overall management of persons with amyotrophic Lateral Sclerosis (ALS)

**INVESTIGATORS**

Ms C Marett

**DEPARTMENT**

Speech Pathology & Audiology

**DATE CONSIDERED**

04.05.07

**DECISION OF THE COMMITTEE\***

Approved unconditionally

**Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.**

**DATE**            04.06.30

**CHAIRPERSON**.....



(Professor PE Cleaton-Jones)

\*Guidelines for written 'informed consent' attached where applicable

cc: Supervisor :            Mrs K levin

**DECLARATION OF INVESTIGATOR(S)**

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10005, 10th Floor, Senate House, University.

I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES



02 AUG 2004

READER'S REPORT: FACULTY OF HUMANITIES  
READER: DR. A. R. PEIRSON

Marett, C (990433V)  
The Impact of Communication Impairment on the Overall Management of  
Persons with Amyotrophic Lateral Sclerosis  
MA (Speech Pathology)

Decision: *Accepted without revision*

The candidate has presented a thorough and detailed proposal. The literature review shows a comprehensive coverage of the relevant literature. The rationale for the study is clear as a consequence of the literature presented. Aims are clearly explicated and research questions follow adequately. The methods suggested seem appropriate. The semi-structured interview seems to address relevant issues and will be fine tuned during a pilot study. Ethics are considered and submission has been made to the ethics committee.

I have no reservations about accepting this proposal.

---

A.R. Peirson (Dr.)

## APPENDIX E

### LETTER OF PERMISSION TO RECRUITING BODIES

University  
of the Witwatersrand,  
Johannesburg



Speech Pathology & Audiology  
School of Human & Community Development

Private Bag 3, Wits 2050, South Africa • Telephone: +27-11-717-4577 • Fax: +27-11-717-4572

29 March 2005

Dear Colleague

My name is Colette Marett and I am a postgraduate student in the discipline of Speech Pathology, at the University of the Witwatersrand. As part of my Masters Degree I am conducting a study on Amyotrophic Lateral Sclerosis (ALS) and communication impairment. The purpose of the study is to establish whether the communication impairment that occurs in ALS, impacts on the management of the disease process.

During the course of ALS many individuals experience a speech deficit known as Dysarthria, which affects speech intelligibility and therefore impairs communication. As the illness progresses the speech impairment becomes increasingly worse, having a negative impact on communicative interactions with friends, family members and possibly those professionals that are involved in the management of the case. Given the nature of the illness most individuals with ALS are likely to require a variety of different interventions (e.g. medical treatment, physiotherapy and psychological attention) and it is of course the right of the person with ALS to indicate his/her preferences regarding the management that he/she would like to receive. However, it is possible that the presenting communication impairment may affect the person's ability to reveal these preferences regarding the management of the case.

It is hoped that by understanding how the communication impairment experienced in persons with ALS impacts on the management of the illness, Speech-Language Pathologists will be able to develop more appropriate means of facilitating communication between persons with ALS and practitioners, and thus facilitate in improving the overall management of ALS.

I therefore wish to conduct a study to ascertain whether impaired communication does affect a person with ALS from conveying his/her preferences of treatment, and hence the management of the illness. In order to complete the study I require interviewing and observing people with ALS, their friends or family members involved in the management of their case, as well as those professionals who treat the individual on a regular basis.

In order to locate such individuals I hereby request permission to gain access to your database to determine whether you have any persons with ALS that meet the criteria specified for the study, and obtain their contact details to establish possible participants for my study. The details obtained would be kept strictly confidential and anonymity is assured.

I have been granted ethical clearance, from the Committee for research on Human Subjects, at the University of the Witwatersrand, and am thus permitted to conduct the study. If you have any queries regarding this study, please do not hesitate to contact me on (011) 849-4618 (home) or 083 302 6762. Furthermore, should you wish to be informed of the results of the study, a summary of the findings will be made available on request.

Thank you.

Yours sincerely

Colette Marett

Research Supervisor: Mrs Karen Levin

## APPENDIX F

### INFORMATION SHEET FOR RESEARCH PARTICIPANTS

University  
of the Witwatersrand,  
Johannesburg



Speech Pathology & Audiology  
School of Human & Community Development

Private Bag 3, Wits 2050, South Africa • Telephone: +27-11-717-4577 • Fax: +27-11-717-4572

#### INFORMATION SHEET

29 March 2005

Hello, my name is Colette Marett

I am a postgraduate student in the discipline of Speech Pathology, at the University of the Witwatersrand. As part of my Masters Degree I am conducting a study on Amyotrophic Lateral Sclerosis (ALS) and communication impairment. The purpose of the study is to establish whether the communication difficulties that are experienced in ALS affect the general management of the condition.

During the course of ALS, many individuals may experience communication difficulties. This means that a person may have trouble speaking, possibly even affecting one's ability to direct personal care, make personal decisions or function in today's environment. As ALS progresses these communication difficulties may become worse and a point in time may be reached when communicating with friends and family members may be very difficult and frustrating. For many people living with ALS it is not uncommon to be receiving treatment from a variety of different professionals, such as the doctor, physiotherapist, psychologist and speech language pathologist for example. However, it may be found that communicating or speaking to these individuals can also be difficult, possibly affecting one's ability to discuss concerns and preferences about treatment. Such difficulties may lead to misunderstandings between the individual concerned and the professional being consulted, resulting perhaps in much unnecessary frustration.

It is hoped that by understanding how speech and communication difficulties experienced in ALS affect the management of the condition, Speech-Language Pathologists will be able to develop more appropriate means of assisting people with ALS communicate, and thereby facilitate in improving the management of ALS.

I have obtained your contact details from the Motor Neuron Disease Association of South Africa and wish to invite you and any friend, family member or caregiver that assists you regularly and is involved in your treatment, to participate in my study, in order to establish whether communication difficulties do affect the management of ALS. In order to complete my study I would like to conduct an interview with you and an important friend, family member or caregiver that assists you on a regular basis (e.g. helping you with daily routines, driving you to appointments or organising your personal affairs). During the interview, I will be asking specific questions for which you need to respond verbally. In the event that you experience difficulty speaking, the interview will be adapted to suit your communication needs. Based on the fact that I wish to understand both your perceptions and a friend, family member or caregiver's perceptions regarding your communication, I will need to conduct both interviews at separate times.

During the course of the interview I will also be required to assess your speech. This assessment will involve additional questions and completing various speech tasks in order for me to rate the clarity of your speech and the effectiveness of your communication. As the management of ALS is seen as a team effort, I would also like to interview all of the professionals (e.g. doctor, physiotherapist, psychologist and speech language pathologist) that are involved in the management of your ALS. This interview would aim to establish how these professionals perceive your communication abilities and whether they feel that certain changes, in terms of communication, may be able to improve their management with you. Thus on completion of the interview, I will ask you to provide the contact details of such professionals.

During each interview and the assessment, a second Speech-Language Pathologist may be present in the room to ensure purely that I conduct the interview in an appropriate manner. The second Speech-Language Pathologist will not actually be involved in interviewing you. Each interview, including the speech assessment, should take approximately 1 to 1½ hours to complete. Both you and your friend, family member or caregiver can be interviewed on the same day or separate days, depending on what is most convenient for you. All responses during each interview will remain strictly confidential and anonymity is assured.

Your participation in the study is voluntary, and refusal to participate will involve no penalties, nor will it be held against you in any way. You are also welcome to withdraw from the study at any time, as well as refuse to answer any questions asked. On completion of the study, all responses from each interview will be destroyed.

If you have any queries regarding this study, please do not hesitate to contact me on (011) 849-4618 (home) or 083 302 6762. Should you wish to be informed of the results of the study, a summary of the findings can be made available to you on request.

Thank you.

Yours sincerely

Colette Marett

## APPENDIX G

### CONSENT FORMS FOR RESEARCH PARTICIPANTS

University  
of the Witwatersrand,  
Johannesburg



Speech Pathology & Audiology  
School of Human & Community Development

Private Bag 3, Wits 2050, South Africa • Telephone: +27-11-717-4577 • Fax: +27-11-717-4572

#### CONSENT FORM FOR THE PARTICIPANT

I hereby consent to participate in your research. I am aware that I will be required to participate in an interview and answer various questions regarding communication and ALS, as well as undertake a speech assessment. I understand that the interview with myself and the interview with my friend / family member / caregiver, must be conducted separately. I am also aware that I will be asked to provide the contact details of any professionals involved in treating me and I understand that those professionals will also be asked questions regarding the management my ALS. I am aware that a second Speech-Language Pathologist may be present during the interview or speech assessment.

I acknowledge that I am aware of the fact that I may withdraw from the study at any time, refuse to answer any questions asked during the interview, or request that the second Speech-Language Pathologist leave the room at any time during the interview. I understand that any information disclosed will remain confidential and will not be shared between the researcher and any other party. It is also understood that anonymity is assured.

Based on this understanding I hereby give Colette Marett permission to use my responses in the write up of the study, and any future publications or presentations.

Date: \_\_\_\_\_

Signature of the participant: \_\_\_\_\_

Signature of the researcher (C. Marett): \_\_\_\_\_

University  
of the Witwatersrand,  
Johannesburg



Speech Pathology & Audiology  
School of Human & Community Development

Private Bag 3, Wits 2050, South Africa • Telephone: +27-11-717-4577 • Fax: +27-11-717-4572

### CONSENT FORM FOR FRIEND / FAMILY MEMBER / CAREGIVER

I am aware that the person I am caring for has given his/her consent to participate in your study and therefore also hereby consent to participate in your research. I am aware that an interview will be conducted where I will be required to answer various questions regarding the communication and management of ALS. I understand that the interview with the person that I am caring for and the interview with myself must be conducted separately.

Furthermore, I understand that I may withdraw from the study at any time, or refuse to answer any questions asked during the interview. I am aware that a second Speech-Language Pathologist may be present during the interview process and that I can request that this person leave the room at any time during the interview. I understand that any information disclosed will remain confidential and will not be shared between the researcher and any other party. It is also understood that anonymity is assured.

Based on this understanding, I hereby give Colette Marett permission to use my responses in the write up of the study, any future publications or presentations.

Date: \_\_\_\_\_

Signature of friend / family member / caregiver: \_\_\_\_\_

Signature of the researcher (C. Marett): \_\_\_\_\_

**APPENDIX H****LETTER OF THANKS FOR RESEARCH PARTICIPANTS**

University  
of the Witwatersrand,  
Johannesburg



Speech Pathology & Audiology  
School of Human & Community Development

Private Bag 3, Wits 2050, South Africa • Telephone: +27-11-717-4577 • Fax: +27-11-717-4572

05-09-2005

Dear \_\_\_\_\_

Thank you very much for agreeing to participate in my study on Motor Neuron Disease. The information that both you and your caregiver provided has been invaluable to my study, and I am very grateful for all your personal experiences that you shared with me. The time that you have both given towards my research project is much appreciated.

Should you be experiencing any communication and/or swallowing difficulties at present, or begin experiencing problems in the future, and wish to seek the advice of a Speech-Language Pathologist, I have provided various contact details below:

- South African Speech-Language Hearing Association – (012) 653-2114. This association will be able to provide you with the contact details of various Speech-Language Pathologists in your area. It is advisable that you request the names of therapists who work in the field of Adult Neurogenic Communication Disorders.
- Speech Pathology & Audiology Department at the University of the Witwatersrand – (011) 717-4567.
- Department of Communication Pathology at the University of Pretoria – (012) 420-2357.

Should you have any queries please do not hesitate to contact me on 083 302 6762.

Kind regards  
Colette Marett



**APPENDIX I**

**THE COMMUNICATION TAXONOMY OF PERCEPTIONS REGARDING THE  
MEDICAL AND REHABILITATIVE MANAGEMENT OF MOTOR NEURON  
DISEASE**

**THE COMMUNICATION TAXONOMY OF PERCEPTIONS REGARDING THE MEDICAL AND REHABILITATIVE  
MANAGEMENT OF MOTOR NEURON DISEASE**

Date of Interview: \_\_\_\_\_

Interviewer: \_\_\_\_\_

Place of Interview: \_\_\_\_\_

Inter-Rater: \_\_\_\_\_

**SECTION A: Personal Information**

*To be completed when interviewing person with MND*

Name / code:	Date of birth:	Gender:
Date of onset of symptoms:		
Date of diagnosis:		
Current symptoms:		
Extent others relied upon for ADL:		
Current daily activities:		
Current or premorbid occupation:		
Members of the Unit:		
Current management received:		
Current communication mode:		
Speech therapy history:		

*To be completed when interviewing caregiver<sup>4</sup>*

Name / code:	Date of birth:	Gender:
Current occupation:		
Relationship to person with MND:		
Number of hours spent with person with MND per day:		
Date of onset of symptoms:		
Date of diagnosis:		
Current symptoms:		
Role in the Unit:		
Formal training received to care for the terminally ill:		
Formal training received for communicating with communicatively impaired individuals:		

---

<sup>4</sup> In this context caregiver refers to any family member, significant other individual, or trained individual that cares for the person with MND on a regular basis.

**SECTION B: Perception-Based Communication Profile**

*To be completed for all participants*

**1. Communicative Style of the Professional**

<b>SPEECH / PARALINGUISTICS</b>	The professional speaks in a clear and understandable manner			
	<b><u>Probes:</u></b>			
	Articulation Rate Quality	Vocal intensity Intelligibility	Intonation Pause	Flow (e.g. stutter) Stress
	<b><u>Comments:</u></b>			

<b>NON-LINGUISTICS</b>	The professional facilitates verbal communication through non-verbal means			
	<b><u>Probes:</u></b>			
	Eye contact Body posture	Proxemics	Facial expressions	Gesture
	<b><u>Comments:</u></b>			

<b>LANGUAGE</b>	The professional's manner of speaking and the content of what is said is easy to understand			
	<b><u>Probes:</u></b>			
	Sentence length	Sentence complexity	Jargon	Complexity of explanations
Turn-taking	Topic initiation	Repair	Quantity of information	
Quality of information	Relevance of information			
<b><u>Comments:</u></b>				

<b>META-LINGUISTICS</b>	The professional thinks about what he/she says when transmitting messages
	<p><b><u>Probes:</u></b>          Aware of miscommunications/breakdowns          Repairs breakdown (how)          Makes modifications to suit individual's needs (what)          Adjusts content appropriately (e.g. jargon)          Topic adherence          Directs conversation to person with MND and/or caregiver (what is preferred)</p>
	<p><b><u>Comments:</u></b></p>
	The professional thinks about messages that are received
	<p><b><u>Probes:</u></b>          Acknowledges contributions from person with MND and/or caregiver          Patient in receiving incoming signals          Probes further when limited information/single word responses are given          Accurate interpretation of incoming signal          Responds appropriately to incoming signal          Willing to facilitate individual's communicative attempts          Aware of miscommunications          Requests clarification</p>
	<p><b><u>Comments:</u></b></p>

<b>INTEGRATION OF SUBSECTION</b>	Additional comments regarding the communicative style of the professional
--------------------------------------	---

2. Communicative Content

<b>TRANSMITTING INFORMATION</b>	The professional provides information about MND
	<p><b><u>Probes:</u></b>            Diagnosis            Possible causes            Course of disease            Expectations for the future            Reviews information provided            Sufficient information for decisions (no harm)            Sense of “hidden information”            Overestimates knowledge            Usefulness of information</p> <p><b>Feeling of being harmed or damaged (physical vs. emotional vs. intentional harm)</b></p>
	<p><b><u>Comments:</u></b></p>



<b>TRANSMITTING INFORMATION</b> (Continued)	The professional provides information about management in general and the future
	<p><b><u>Probes:</u></b></p> <ul style="list-style-type: none"> <li>Recommends appropriate management &amp; options</li> <li>Rationale for recommendations</li> <li>Side effects</li> <li>Length &amp; duration</li> <li>Effectiveness</li> <li>Implications (financial; time)</li> <li>Support groups</li> <li>Living wills</li> <li>Sufficient information for informed decisions</li> <li>Overestimates knowledge (harmful)</li> <li>Collaborative decision-making within the Unit</li> </ul>
	<p><b><u>Comments:</u></b></p>

<b>RECEIVING INFORMATION</b>	The communicative behaviours of the professional acknowledge the person with MND and/or the caregiver's needs
	<p><b><u>Probes:</u></b>          Listens attentively to person and/or caregiver          Clarifies information/re-explains information misunderstood          Gives person time to convey his/her message          Inappropriate interruptions          Opportunity for questions          Provides comfort beyond the facts          Acknowledges individual opinions          Sense of confidentiality/privacy          Listens, acknowledges, acts on the person with MND and/or the caregiver's decisions</p>
	<p><b><u>Comments:</u></b></p>

<b>INTEGRATION OF SUBSECTION</b>	Additional comments relating to communicative content
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### 3. Healthcare Consumer-Professional Relationship

<b>PERSON WITH MND</b>	The communicative behaviours of the professional acknowledge the individual with MND as a person
	<p><b><u>Probes:</u></b></p> <p>Treated with compassion          Makes self available          Warm, friendly &amp; empathetic          Acknowledges person's preferences          Acknowledges person's limited medical knowledge          Offers encouragement          Involved in decision-making          Does best to promote health and well-being          Sense of being told the truth          Respects person's decisions          Dealt with confidentially          Sense of honesty in the relationship          Sense of lies/broken promises          Ignores/cutting off          Gives time of day          Delivers information in a tactful manner that is not disrespectful/burdensome          Waiting times/ability to get appointment          Offers maximum support          Understands individual's experience of MND</p>
	<p><b><u>Comments:</u></b></p>

<b>CAREGIVER</b>	The communicative behaviours of the professional acknowledge the caregiver as a person
	<p><b><u>Probes:</u></b>  Warm, friendly &amp; empathetic  Acknowledges that caregiver knows the person well – decision making  Support  Respects decision making  Does best to promote well being  Makes self available (e.g. phone calls)  Sense of lies/broken promises  Ignores/cutting off  Sense of being told the truth/honesty  Delivers information in a tactful manner that is not disrespectful/burdensome  Gives time of day  Dealt with confidentially  Put at ease &amp; gives reassurance  Understands individual’s experience of MND</p>
	<p><b><u>Comments:</u></b></p>

<b>INTEGRATION OF SUBSECTION</b>	Additional comments relating to the healthcare consumer-professional relationship
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#### 4. The Person with MND as a Communicator

<b>TRANSMITTING INFORMATION</b>	The person with MND is able to transmit messages effectively
	<p><b><u>Probes:</u></b>          Articulation          Vocal quality          Intelligibility          Non-verbal communication          Alternate communication          Sentence length &amp; complexity          Topic initiation          Aware of breakdown          Topic repair          Turn taking          Topic adherence (provision of relevant subjective information)          Asks questions          Willing to transmit own opinions, preferences and decisions          Truthful and honest about own concerns regarding health          Kept any promises made with professional</p>
	<p><b><u>Comments:</u></b></p>

<b>RECEIVING INFORMATION</b>	The person with MND is able to receive messages and act on them
	<p><b><u>Probes:</u></b>          Aware of miscommunications          Requests clarification          Accurate interpretation of incoming messages          Listens and acknowledges information received          Acknowledges professional's opinion          Asks questions for information that is difficult to understand</p>
	<p><b><u>Comments:</u></b></p>

<b>INTEGRATION OF SUBSECTION</b>	Additional comments relating the communication of the person with MND
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**SECTION C: Concluding Comments**

Can you comment on whether you feel the management of MND is influenced by the communication impairment?

**Do you feel that the professional's communication skills are representative of his/her interactions with all patients, regardless of the communication impairment?**

Which members of the Unit do you feel are most effective in terms of their communication abilities?

**What changes should persons with MND make to improve their communicative interactions with professionals?**

**What changes should professionals make to improve their communicative interactions with persons with MND and other members of the Unit?**

**APPENDIX J**

**FOCUS GROUP CLEARANCE CERTIFICATE**

Human Research Ethics Committee (Medical)  
(formerly Committee for Research on Human Subjects (Medical))

Secretariat: Research Office, Room SH10005, 10th floor, Senate House • Telephone: +27 11 717-1234 • Fax: +27 11 339-5708  
Private Bag 3, Wits 2050, South Africa

University  
of the Witwatersrand,  
Johannesburg



8 October 2003

Colette Marett  
Department of Speech Pathology  
School of Human & Community Development  
Umthombo Building  
University

Dear Colette

**RE: PROTOCOL M040420**

This letter serves to confirm that the Deputy Chairman of the Human Research Ethics Committee (Medical) has approved your request on the abovementioned protocol. Copy attached.

Yours sincerely

A handwritten signature in black ink, appearing to be 'Anisa Keshav'.

Anisa Keshav (Ms)  
Secretary  
Human Research Ethics Committee (Medical)



**APPENDIX K****INFORMATION SHEET FOR FOCUS GROUP PARTICIPANTS**

Speech Pathology & Audiology  
School of Human & Community Development

Private Bag 3, Wits 2050, South Africa • Telephone: +27-11-717-4577 • Fax: +27-11-717-4572

University  
of the Witwatersrand,  
Johannesburg

**INFORMATION SHEET FOR ETHICIST**

20 September 2005

Dear Ethicist

My name is Colette Marett and I am a postgraduate student in the discipline of Speech Pathology, at the University of the Witwatersrand. As part of my Masters Degree I am conducting a study on Amyotrophic Lateral Sclerosis (ALS) and communication impairment. The purpose of the study is to establish whether the communication impairment that occurs in ALS, impacts on the overall management of the illness process.

During the course of ALS many individuals experience a speech deficit known as Dysarthria, which affects speech intelligibility and therefore impairs communication. As the illness progresses the speech impairment becomes increasingly worse, having a negative impact on communicative interactions with friends, family members and possibly those professionals that are involved in the management of the case. Given the nature of the illness most individuals with ALS are likely to require a variety of different interventions (e.g. medical treatment, physiotherapy and psychological attention) and it is of course the right of the person with ALS to indicate his/her preferences regarding the management that he/she would like to receive. However it is possible that the presenting communication impairment may affect the person's ability to reveal these preferences regarding the management of the case, and thus give rise to various ethical dilemmas.

It is hoped that by understanding how the communication impairment experienced in persons with ALS impacts on the management of the illness, Speech-Language Pathologists will be able to develop more appropriate means of facilitating communication between persons with ALS and practitioners, and thus facilitate in improving the overall management of ALS.

In order to ascertain whether impaired communication does affect a person with ALS from conveying his/her preferences of treatment, thus affecting the management of the illness and giving rise to different ethical concerns, I have conducted face-to-face interviews with various persons with ALS, as well as their caregivers. Part of the analysis of my data is to identify the different ethical dilemmas that arise in the management of this condition. In order to compliment my analysis and report the findings in the most objective manner as possible, I wish to conduct a focus group with various ethicists so as to discuss the data obtained and establish the perceptions of such individuals who are knowledgeable in the field of Ethics.

I have obtained your contact details from Professor Cleaton-Jones, and hereby wish to invite you to participate in the focus group that I will be conducting. Given your knowledge and

experience in the field of Ethics, I would appreciate establishing your perceptions and ideas with regards to the various ethical dilemmas that I have identified as occurring currently in the management of ALS. During the focus group I will be presenting my findings, and a discussion will then be held whereby you and other ethicists will be given an opportunity to provide input on the different concerns that are raised. In addition, the discussion that arises during the focus group will be tape recorded so as to capture all contributions made by participants.

The focus group will run for approximately two hours and will be conducted at a time most convenient for you. All responses that you provide during the discussion will remain strictly confidential in the write up of the study, and anonymity is assured. It should however be noted that your identity at the time of the focus group cannot be protected in view of the fact that several ethicists besides yourself, as well as various Speech-Language Pathologists, will be invited to attend this group. Participation in the study is voluntary and refusal to participate will involve no penalties, nor will it be held against you in any way. You may withdraw from the study at any time, as well as refuse to answer any questions asked to you. At any time the tape recorder may be switched off at your request. On completion of the study all tape recordings will be destroyed.

If you have any queries regarding this study or the focus group itself, please do not hesitate to contact me on (011) 849-4618 (home) or 083 302 6762 (cell). Furthermore, should you wish to be informed of the results of the study, a summary of the findings will be made available on request.

Thank you.

Yours sincerely

Colette Marett

**APPENDIX L****CONSENT FORM FOR FOCUS GROUP PARTICIPANTS**

Speech Pathology & Audiology  
School of Human & Community Development

Private Bag 3, Wits 2050, South Africa • Telephone: +27-11-717-4577 • Fax: +27-11-717-4572

**CONSENT FORM FOR THE FOCUS GROUP**

I hereby consent to participate in your focus group. I am aware that my attendance at the group will require my discussing various ethical dilemmas that are raised, along with other ethicists present at the meeting. Furthermore, I understand that the entire group discussion will be tape recorded, and that at any time I may request the tape recorder to be switched off.

I acknowledge that I am aware of the fact that I may withdraw from the study at any time or refuse to answer any questions asked during the discussion. It is understood that any information disclosed will remain confidential in the write up of the study and anonymity is therefore assured. However, at the focus group session it is realised that my identity cannot be protected in the presence of other ethicists and Speech-Language Pathologists present.

Based on this understanding I hereby give Colette Marett permission to use my responses in the write up of the study, and any future publications or presentations.

Date: \_\_\_\_\_

Signature of the ethicist: \_\_\_\_\_

Signature of the researcher: \_\_\_\_\_

**APPENDIX M**

**CONSENT FOR TAPE RECORDING OF FOCUS GROUP**

University  
of the Witwatersrand,  
Johannesburg



Speech Pathology & Audiology  
School of Human & Community Development

Private Bag 3, Wits 2050, South Africa • Telephone: +27-11-717-4577 • Fax: +27-11-717-4572

**CONSENT FORM FOR THE TAPE RECORDING OF THE FOCUS GROUP**

I hereby consent to the tape recording of the focus group. It is understood that at any time during the meeting I may request the tape recorder to be switched off. I am aware that all information obtained will remain confidential as far as possible, and that on completion of the study the tape recordings will be destroyed.

Date: \_\_\_\_\_

Signature of the ethicist: \_\_\_\_\_

Signature of the researcher: \_\_\_\_\_

**APPENDIX N****THEMES COMMON TO PERSONS WITH MND**

	UNIT 1	UNIT 2	UNIT 3	UNIT 4	UNIT 5	UNIT 6
1. Swallowing / feeding	•	•				•
2. Speech-language pathology	•	•	•	•	•	•
3. Withholding information	•				•	•
4. Patient communication skills	•	•	•	•		•
5. Emotions	•	•	•	•		•
6. Decision-making	•	•	•			
7. Information	•	•	•	•	•	•
8. Living will	•		•	•		
9. Hope / encouragement	•	•		•		•
10. Harm	•	•	•	•		•
11. Professional communication skills	•	•	•	•		•
12. Informed decisions	•		•	•		•
13. Rehabilitation referrals	•	•	•	•	•	•
14. Compassion / warmth / friendliness	•	•	•	•	•	•
15. Patient preferences / opinions	•	•	•			•
16. Truth-telling / hidden information	•	•	•			•
17. Support	•		•	•	•	•
18. Treatment: patient versus family	•	•				
19. Management of MND	•	•		•	•	•
20. Follow-up appointments	•				•	
21. Professional lack of knowledge	•	•	•	•		
22. Changes to be made	•	•	•	•	•	•
23. Coping with MND	•				•	
24. Medical aid / finances	•	•		•	•	
25. Questions	•	•	•	•	•	
26. Attitude that nothing can be done	▪	•	•	•	•	•
27. Alternative medicine		•	•	•		
28. MND Association		•	•			
29. Work-up to diagnosis		•	•			•
30. Hospice		•				
31. Availability of professionals		•			•	
32. Professionals who do not listen		•			•	
33. Physiotherapy	•		•			
34. Nothing to lose			•		•	
35. Health & well-being			•			
36. Stem cell therapy				•		
37. Support groups				•	•	•
38. AAC				•		
39. Professionals' personal opinions	•			•		•
40. Time of diagnosis					•	
41. Internet		•	•	•	•	
42. Denial					•	
43. Family	•				•	
44. Reassurance	•		•			•

**THEMES COMMON TO FAMILY MEMBERS**

	UNIT 1	UNIT 2	UNIT 3	UNIT 4	UNIT 5	UNIT 6
1. Swallowing / feeding	•		•			•
2. Speech-language pathology	•	•	•			•
3. Withholding information	•					•
4. Patient communication skills	•		•			•
5. Emotions	•	•	•			•
6. Decision-making	•	•		•		
7. Information	•	•	•	•		•
8. Living will	•		•			
9. Hope / encouragement	•	•	•	•		•
10. Harm	•		•	•		•
11. Professional communication skills	•	•	•	•		•
12. Informed decisions	•			•		•
13. Rehabilitation referrals	•	•	•	•		•
14. Compassion / warmth / friendliness	•	•	•	•		•
15. Patient preferences / opinions	•	•				
16. Truth-telling / hidden information	•	•		•		•
17. Support	•	•	•	•		•
18. Treatment: patient versus family	•		•	•		•
19. Management of MND	•	•		•		•
20. Follow-up appointments	•	•	•			•
21. Professional lack of knowledge	•	•		•		•
22. Changes to be made	•	•	•	•		•
23. AAC	•	•				
24. Health & well-being	•			•		
25. Support groups	•			•		•
26. Formal training	•	•	•			•
27. MND Association	•	•	•			•
28. Medical Aid / finances		•		•		•
29. Attitude that nothing can be done		•	•	•		•
30. Alternative medicine		•	•			
31. Questions	•	•	•	•		•
32. Institutional care		•				
33. Coping		•	•			
34. Public awareness	•	•				•
35. Work-up to diagnosis			•			
36. Availability of professionals	•		•			•
37. Professionals who do not listen			•			
38. Stem cell therapy				•		
39. Nothing to lose				•		
40. Quality of life	•			•		•
41. Denial				•		
42. Internet	•	•	•	•		•
43. Professionals' own opinions						•